CARERS TRUST
Sefton Carers Centre

Sefton Carers Centre

2024
ANNUAL SURVEY

Published October 2024

CONTENTS

FOREWORD

Sefton Carers Centre, Chief Executive Officer, 2024 Survey Comments

This report summarises our findings from responses to our 2024 survey. I would like to take this opportunity to thank all unpaid carers who took the time to complete the survey.

The survey was sent to all unpaid carers registered with Sefton Carers Centre via email. 500 hard copies were posted from a random sample of unpaid carers who had received services from Sefton Carers Centre, 12 months prior to the survey commencement. We also produced new sections in the survey to focus on parent carers and young adult carers.

The survey findings will enable Sefton Carers Centre and partners to review evidence and inform on developments within the Sefton All Age Carers Strategy and Action Plan which will direct future services and support for carers in Sefton.

We can review the findings under the 6 Themes:

Early Identification

One of the themes from the survey was the importance for carers to be identified early in their caring role. We are therefore increasing our marketing and awareness raising of carers over the next 12 months. We will develop targeted marketing at health professionals, focus on hospital discharge and work with schools and universities. Currently Sefton Carers Centre provides training to schools and professionals to recognise, understand and support carers. However, we have identified a gap in this training provision around Parent Carers Professionals Awareness and will look to develop this area.

Carers Assessments

The survey identifies the need for investment in carers assessments. We are aware that adult carers assessment referrals are increasing which is resulting in a delay to carers to receiving assessments. As carers are also entitled to an annual carers reassessment the service is compounded as the numbers will always increase year on year. Sefton Carers Centre and Sefton Council have increase resources in delivering carers assessments to support the process and will constantly monitor the service. Parent Carer Needs Assessments are also highlighted in the survey as an area which needs development. Sefton Council are working with Sefton Carers Centre to review all aspects of Parent Carer Needs Assessments and are planning to refresh the process over the next 12 months.

Empowering Carers

Empowering Carers is another area highlighted within the survey. Counselling appointments and mental health is important to carers. Currently Sefton Carers Centre provides counselling support for adult carers and Listening Ear Service. Both services are delivered by volunteers and recruitment of volunteers, at Diploma level, can be challenging against demand. We recognise the importance of counselling and will review our processes to support carers waiting times.

Information & Advice

The survey highlights the importance of the right information at the right time. We have progressed in this area with the development of a new website. The new website will be easier to navigate, link to relevant information for unpaid carers, provide more online forms rather than downloads and we will increase the number of 3 min videos over a range of services.

We have also invested in a new telephone system to enable more options for carers and ensure they are informed within their contact with Sefton Carers Centre.

Health & Well-being

Another area of the survey focused on health and well-being of unpaid carers, we will focus our activities provision to support health and well-being and link in with partner organisations to promote opportunities to unpaid carers. Our carers assessments already have a priority focus in this area, and we will look to promote opportunities to meet this need. Some work has already commenced with the developments around emergency planning for unpaid carers and access to CarersSmart, a free discount and lifestyle card service. Sefton Carers Centre also offers tailored support via our partnership with Living Well Sefton.

Young Carers

The survey evidence the need to support young adult carers with tailored support in education, employment and health and wellbeing. This will form elements of the carers strategy action plan. We will focus support on transition and work with universities to enable young carers to achieve their ambitions. Young Carers voice will be supported via the new carers voice and involvement project.

INTRODUCTION

The survey was conducted during July 2024 and was open for the whole of the month.

Carers were advised of the survey via email link, and via the same link on the Carers Centre web pages.

Carers who had some involvement with the centre over the last 12 months were posted out a copy of the survey.

Other local community and voluntary organisations were also aware and supporting the raising of awareness of the survey.

The survey was broken down into sections to enable more specific elements of the carers role to be identified.

- The first section was generic for all carers to complete and provided some demographics etc.
- The second section was focused on carers who supported Adults.
- The third section focused on those who are Parent Carers.
- The fourth section focused on Young Carers between 16-24 years.
- The last section focused on the services specifically provided through the Carers Centre and could be completed by all carers.

A total of 757 responses were received

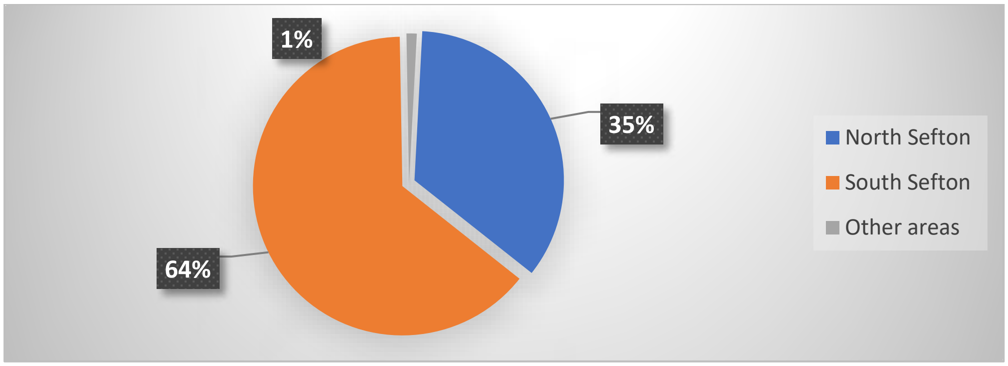
- 300 partially completed
- 457 completed the survey

Numbers of responses are provided in the report but will reflect the range of carers and the type of response, for example some questions offered multiple choice. This may account for the variance of fully or partially completed surveys. Overall, most generic questions received around 450 responses.

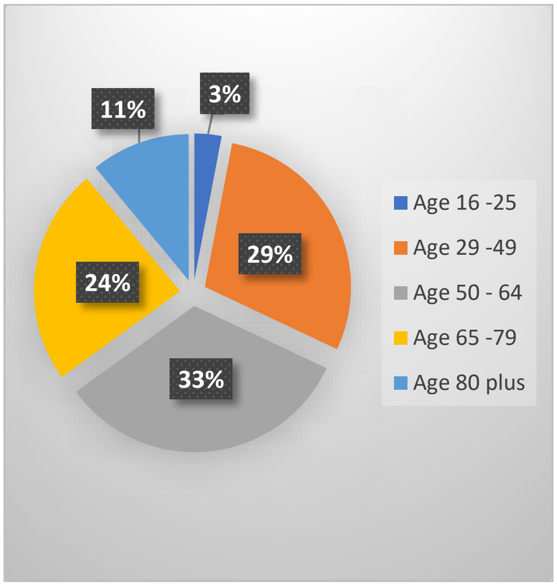
SECTION 1

GENERAL RESPONSES FOR ALL CARERS

LOCATION OF CARERS – across the South Sefton area based upon the numbers of carers who responded there are approx. double the level of carers as opposed to those in north Sefton. (*451 carers completed this question*).



AGE RANGE OF CARERS



Based upon the respondents - total 452

The highest proportion of carers were those aged between 50 -64 at 33%

Followed by those aged 26-49 at 29%

Next those aged 65-74 at 24%

CARER STATUS – CURRENTLY CARING OR NOT WITHIN THE LAST 12 MONTHS

Based upon the responses completed (451)

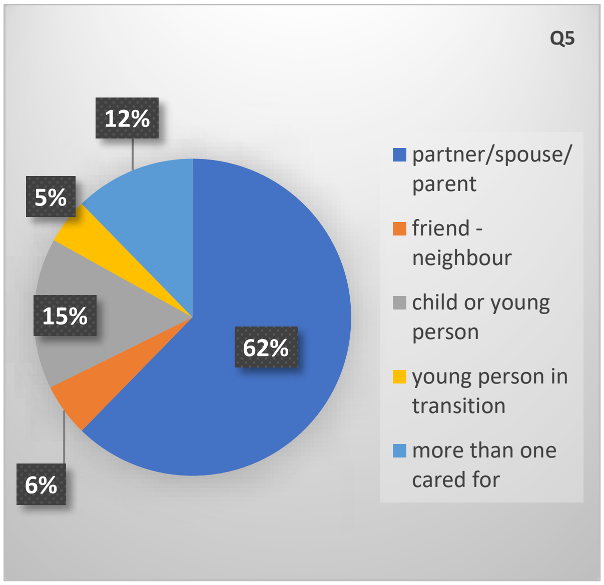
- *96% of carers are currently caring*
- *2% of carers are not currently caring*
- *2% were unsure*

IF YOU HAD TO STOP CARING IN THE LAST 12 MONTHS WHAT WAS THE REASON

(81% of the 437 respondents were still caring however those who had stopped reasons below):

11%	*Cared for passed away*
10	*Cared for is now in long term care*
9%	*Impact on my own health & wellbeing*
4%	*Impact of financial pressure*
3%	*Difficulty with travelling to care*
2%	*Other*

WHO ARE YOU CARING FOR:



More than one cared for could describe where a carer has multiple caring roles. i.e. supporting both a child/young person as well as elderly parents, or a spouse as well as elderly parents.

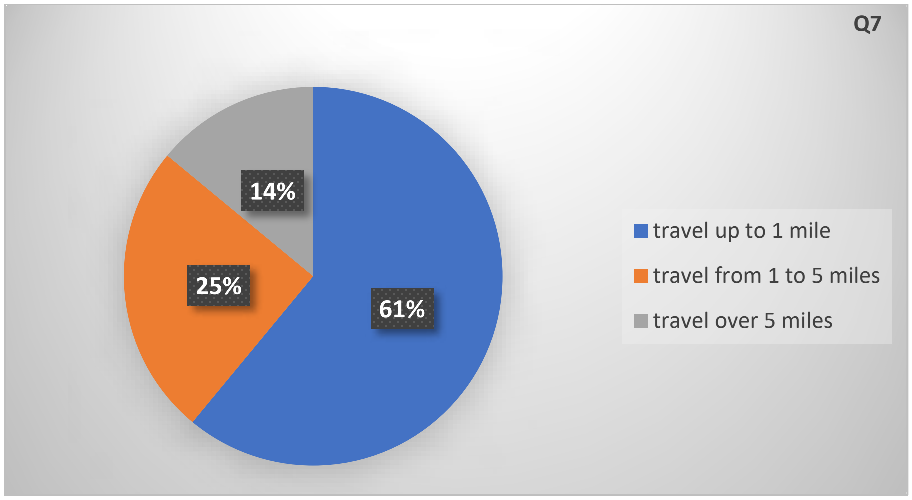
They may also account for carers with more than one child.

DOES THE CARED FOR LIVE IN THE SAME HOME AS THE CARER –(449 RESPONDENTS)

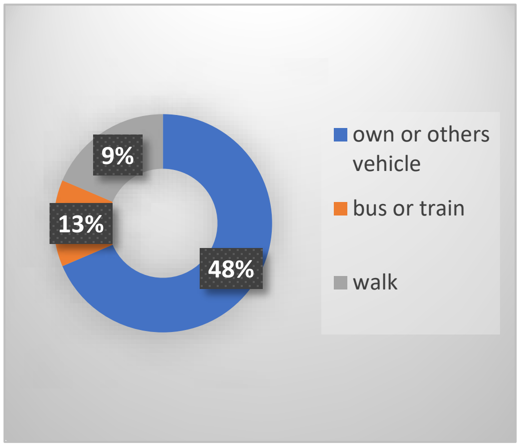
- *80% of respondents said yes*
- *13% of respondents said no*
- *7% of respondents said both*

Where the respondent stated both this could be for a child and partner, or where elderly parent is residing with the carer alongside a partner. There could be a range of variables however this indicates the additional pressure on the carer.

WHERE THE CARED FOR DOES NOT LIVE WITH THE CARER HOW FAR DO THEY TRAVEL TO CARE (176 RESPONDENTS)



WHAT METHOD OF TRANSPORT IS USED



48% of carers use a motor vehicle to travel with 6% of those relying upon other persons to transport them.

9% used a bus or train

13% walked

HOW MANY HOURS PER WEEK DO YOU SPEND CARING

53% of carers provide above 50 hours per week

22% provide between 20 -49 hours per week

18% provide between 5-19 hours per week

7% provide up to 5 hours per week

OTHER COMMITMENTS WORK OR STUDY

60% of carers do not work or study

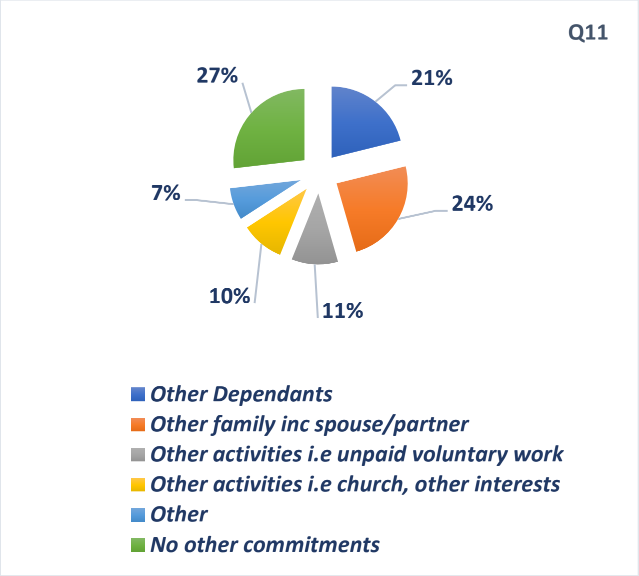
20% work or study full time

17% work or study part time

3% work and study

Around 60% of people providing care are aged between 50 and 80 years which may indicate why the highest proportion of people caring are not employed or studying. Many carers express that they have their own disability or have given up employment of study which also impacts on this.

DO YOU HAVE OTHER COMMITMENTS ALONGSIDE YOUR CARING ROLE. (434 RESPONDENTS)



Other dependents could be children with some being disabled

One carer commented she had to care for her father and her grandchildren

Other have multiple caring roles for family, and friends, neighbours etc

DO YOU MANAGE TO GET ANY TIME FOR YOURSELF. (448 RESPONDENTS)

43% of carers stated they rarely have time for themselves

41% of carers stated they did on occasion

16% said they did manage to get some time for themselves

Caring takes up all my time

I have no time except walking the dog

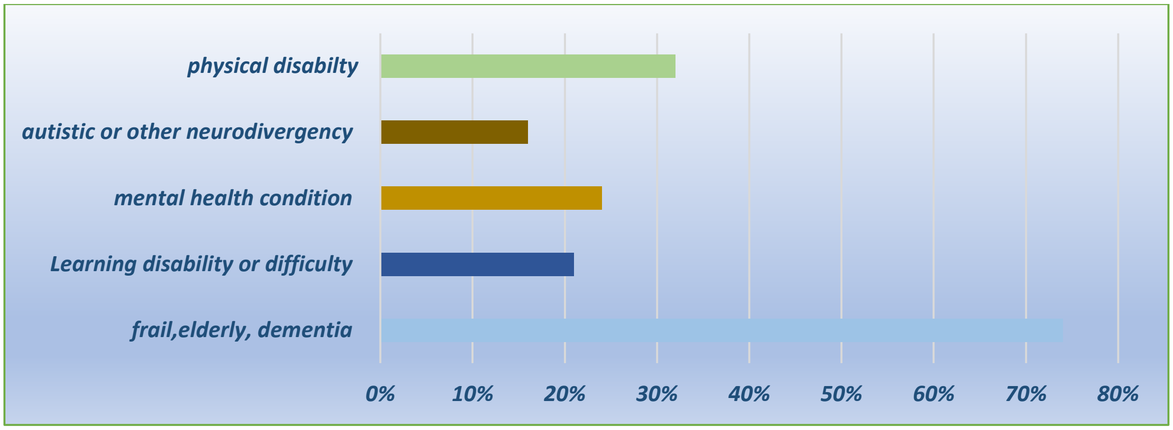
I have 2 sons with ASD/LD and 1 with ADHD plus my partner and I have our own medical issues

Have given up voluntary work to undertake caring

OUTCOMES SECTION 3. --

SPECIFIC TO CARERS SUPPORTING ADULTS

TYPE OF DISABILITY (THE CARED FOR) (427 RESPONSES)



Carers could pick more than one disability and so several carers did express dual diagnosis of those they cared for.

DID YOU FIND IF DIFFICULT TO GET THE RIGHT INFORMATION WHEN YOU FIRST BECAME A CARER. (428 RESPONSES)

53% -- Found -- Not finding the right information and that finding support was difficult and confusing.

16% -- Found --- that there was a lack of connectivity between the statutory services.

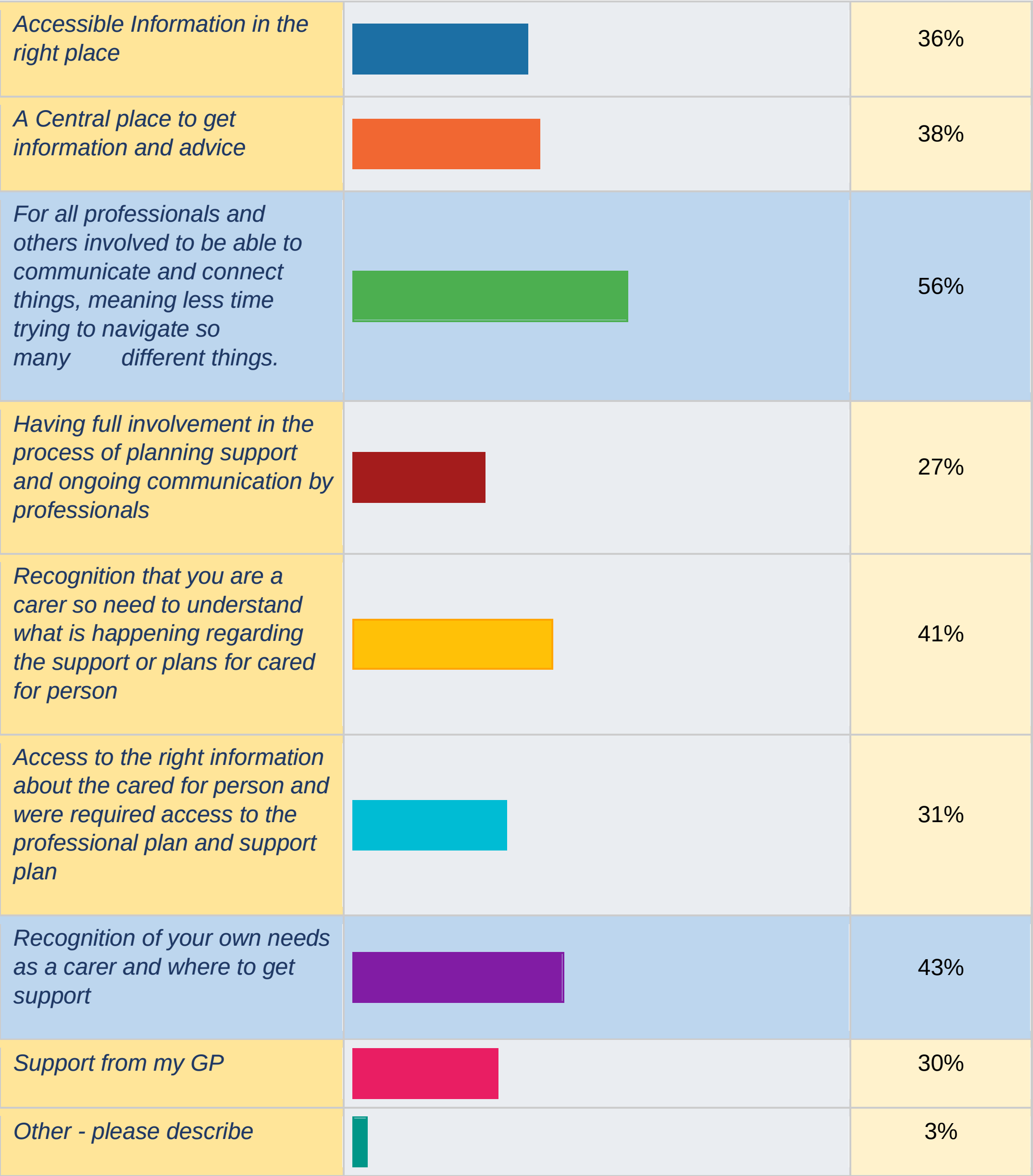
When children and husband were diagnosed, was just given a diagnosis, no mention of where we could seek support.

Was very isolated at the beginning - was unable to leave home to access support None of the benefit agencies were helpful or supportive

Overwhelmed, as so much information out there (internet) but difficult to sort out the reliable info from the rest.

GP and Social Services do not seem to communicate!

WHAT MIGHT HAVE HELPED WHEN YOU FIRST STARTED CARING (409 RESPONSES)



Accessible Information in the right place	36%
A Central place to get information and advice	38%
For all professionals and others involved to be able to communicate and connect things, meaning less time trying to navigate so many different things.	56%
Having full involvement in the process of planning support and ongoing communication by professionals	27%
Recognition that you are a carer so need to understand what is happening regarding the support or plans for cared for person	41%
Access to the right information about the cared for person and were required access to the professional plan and support plan	31%
Recognition of your own needs as a carer and where to get support	43%
Support from my GP	30%
Other - please describe	3%

It can be very easy to feel overwhelmed by the complexity of a loved one's new condition.

Complete lack of multi-disciplinary communication,

Just no idea at all what help I can get ….. its very overwhelming

It would be helpful to be guided through things in a positive way and would help carers in general!

Found it very difficult in getting the right information from many sources

WHAT MADE YOUR CARING ROLE MORE DIFFICULT. (424 RESPONSES)

Financial issues- pressures	🟩	**39%**
Transport issues	🟧	**17%**
Lack of respite or carer breaks when you need them	🟩	**42%**
Lack of access to day time support	🟧	**17%**
No clear guidance on alternative long term support options for adults under 65 - i.e. supported living	🟧	**19%**
Lack of clear guidance on residential and nursing care options for people over 65, including paying for care	🟦	**23%**

Lack of information on other services either statutory or non statutory services and how to access them	🟩	**32%**
Getting appointments at a time when I can so I can support the cared for	🟩	**31%**
Feeling like I cannot ask for help	🟦	**22%**
Pressure albeit understandable from the cared for person or other family members	🟦	**28%**
Isolation and feeling alone	🟩	**35%**
Lack of support from other family members	🟦	**28%**
Other - please outline	🟧	**4%**
None	⬜	**6%**

"Professionals in the LA to be caring, compassionate and wanting to help, rather than put up barrier after barrier".

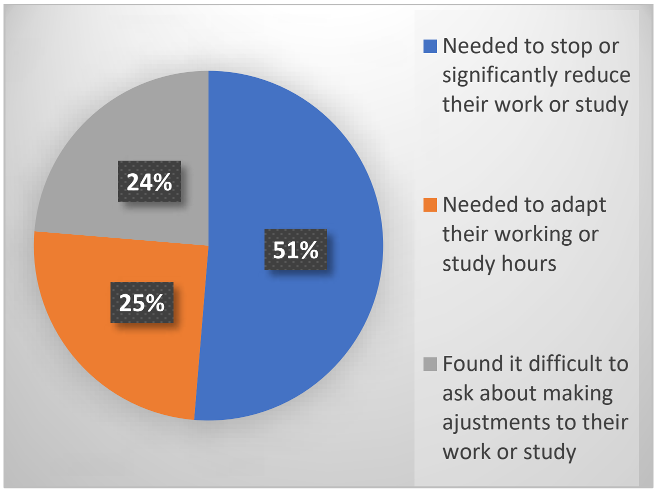
"I needed to be shown how to dress/undress washing practical aspects, with someone in so much pain without hurting them"

"Help is out there but carers need different sorts of help at different times especially with dementia".

"I was surprised at how many things made the caring roll so stressful and being kept 'out of the loop' at times really compounded this".

IMPACT ON WORK, STUDY OR OTHER COMMITMENTS (424 RESPONSES)

For those carers who worked or studied



Who is supposed to help people in this position Social Services are not interested if the person's savings are above the threshold.

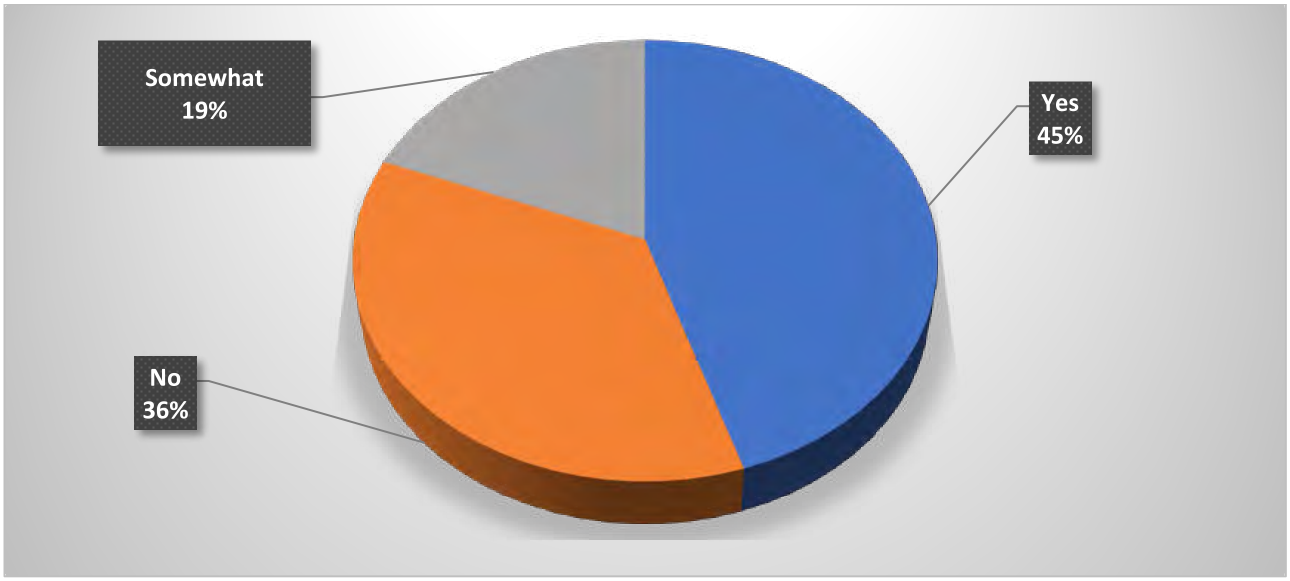
have concerns about what happens to my son when I pass away –

Everyone assumed I would give up my life and plans and become a carer (including medical professionals)

Total lack of support generally

Lack of staff and many missed appointments

HAVE YOU HAD TO REDUCE OR GIVE UP WORK OR STUDY TO CARE ((414 RESPONSES)



"I have to reduce work - eventually deciding to significantly retire at 60 I had to draw down a pension early"

"I had to give up my full time job to be an effective carer, at great financial inconvenience"

"Had to shut down my business"

"Went part time and eventually retired early"

"I was hoping to do some travelling but now I can't because I'm caring"

HAVE YOU FOUND IT DIFFICULT TO ASK TO BE ABLE TO ADAPT YOUR WORK OR STUDY TO SUPPORT YOUR CARING ROLE (384 RESPONSES)

18%	*Yes*
12%	*No*
17%	*For some*
52%	*NA*

- *I am extremely lucky that my employer is fully aware of the difficulties of looking after a parent with dementia*
- *I had to plead with my manager to keep my mobile phone on me*
- *manager had no understanding and was very inflexible*
- *Fortunate to have an understanding boss*
- *having to negotiate with my employer*

DO YOU FEEL YOUR CARING ROLE ADDS PRESSURE TO YOUR FINANCES

47% responded - Yes

24% responded - No

Carers support is not enough to support you when not being able to work.

We are nowhere near the minimum wage.

I am the only wage earner in the family

Can't pay bills, fallen into debt.

As we are on benefits its sometime a bit of a financial strain such as shopping

Massive financial pressure

HAVE YOU BEEN ABLE TO ACCESS ANY WELFARE BENEFITS AS A CARER (428 RESPONSES)

Yes	38%
No	36%
Benefits are not sufficient	15%
Not Applicable	11%

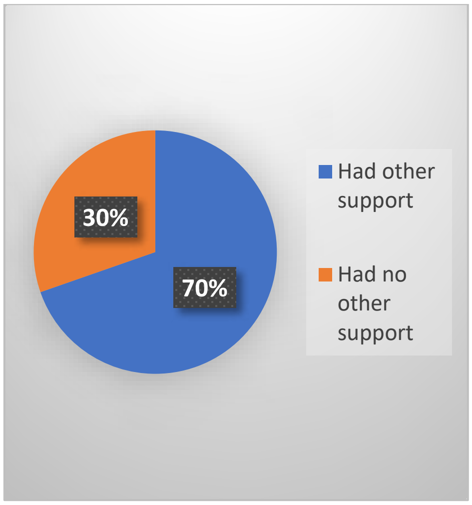
DO YOU FEEL YOU MAY HAVE TO GIVE UP YOUR CARING ROLE DUE EITHER FINANCIAL OR IMPACTS ON YOUR OWN HEALTH AND WELLBEING (425 RESPONSES)

Yes	39%
No	21%
Sometimes	41%

For this question there were **75** comments left by carers some of which are below, the overarching theme through most was the impact of caring on the carer's own health and wellbeing, some were also disabled or aging and were feeling overwhelmed.

- *No carers allowance after 65, but still caring*
- *Own health*
- *Due to my own health concerns and mental health*
- *The bleakness of the situation is overwhelming.*
- *As I am 80 years old, I have some concerns of how I would cope long term as I get even older.*
- *I am 91 so sometimes find tasks demanding and/or tiring*
- *I was unable to cope*
- *Feel lonely and as I age, I have no future*
- *I find it very stressful*

DO YOU HAVE SUPPORT FROM OTHERS I.E. FAMILY OR FRIENDS (422 RESPONSES)

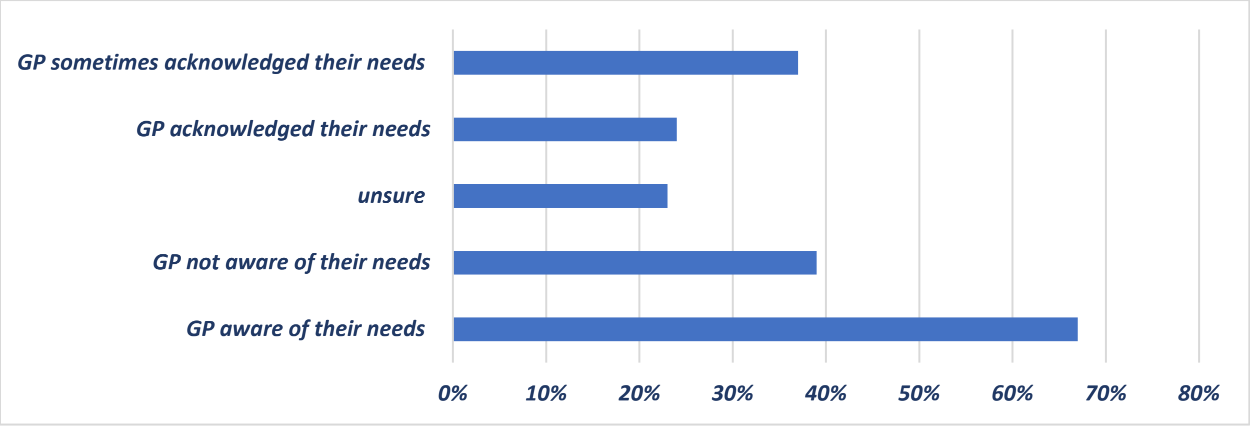


62% of carers stated they had other support available to help them.

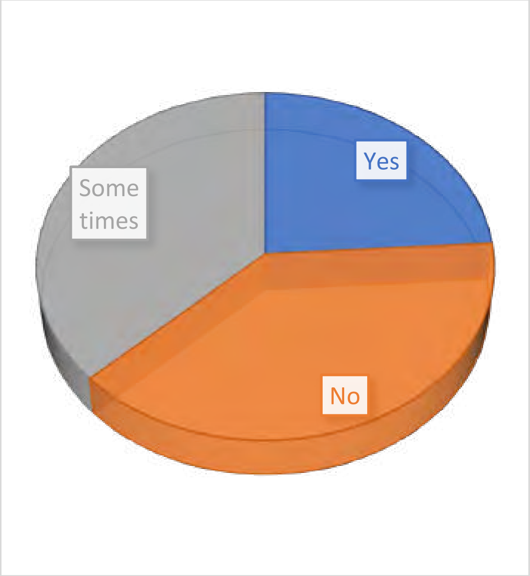
27% of carers stated they had no other help available to them.

There were 91 comments added to this response – all stressing the added pressures on families or where family are not close etc

DOES YOUR GP KNOW YOU ARE A CARER. (422 RESPONSES)

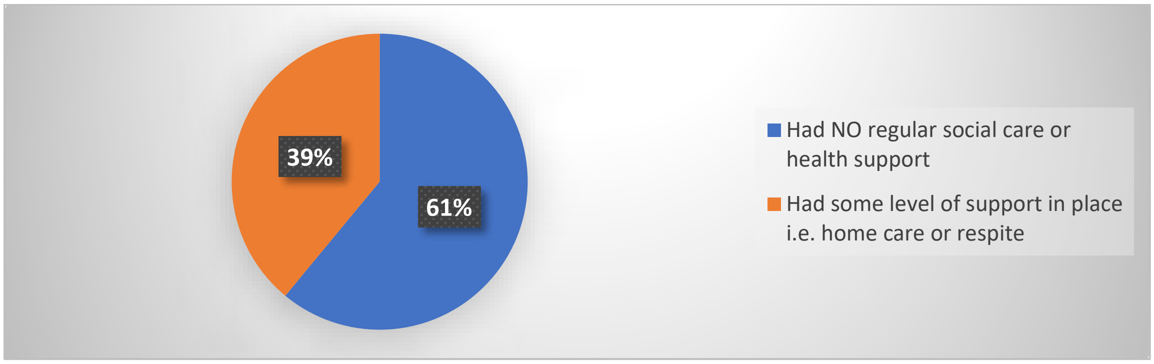


DOES YOUR GP ACCOMMODATE YOUR NEEDS AS A CARER (430 RESPONSES)



- *They don't offer anything additional to carers.*
- *They try to give me appointments around my caring commitments*
- *The link worker from surgery has been great. Sending me links to organisations such as caring, ringing and emailing me*
- *They knew I was a Carer but did nothing to support me.*
- *I have to consistently tell them it is a struggle*
- *I have an extremely supportive GP*
- *The GP still seems to find it difficult to accept my presence in the room as a carer which my carer has appointments*

DOES THE CARED FOR HAVE ANY SOCIAL CARE SUPPORT IN PLACE. (416 RESPONSES)



WHERE SERVICES ARE IN PLACE ARE THESE PROVIDED BY THE COUNCIL OR DOES THE CARED FOR PERSON PAY FOR SERVICES THEMSELVES (417 RESPONSES)

Services are funded fully by the cared for person - (Self funding)		***15%***
Social Services fund care (there may be an assessed financial contribution)		***23%***
Unsure		***11%***
No Services in place		***51%***

ARE ANY OF THE SERVICES PROVIDED USING A DIRECT PAYMENT (398 RESPONSES)

53%	*Had services provided via a direct payment*
67%	*Had no services in place*

DOES THE CARED FOR HAVE ANY SERVICES PROVIDED BY HEALTH NHS –(423 RESPONSES)

Care at home funded by health		***11%***
Palliative care		***6%***
District nursing		***11%***
Regular health therapies, including physical therapy, psychological support, mental health support,		***14%***
Medical or health appointments to manage an ongoing condition		***39%***
Short term health appointments /interventions		***14%***

Regular input from the community mental health services, or learning disability services	🟪	***13%***
Other please describe in the comments box	🟥	***3%***
No Services in place	🟩	***41%***

DOES THE CARED FOR HAVE A PERSONAL HEALTH BUDGET

Yes	🟦	***14%***
No	🟧	***25%***
Unsure	🟩	***17%***

DO YOU MANAGE THE ARRANGEMENTS FOR THE DIRECT PAYMENT OR PERSONAL HEALTH BUDGET

24% of carers stated that they were managing the DP or PHB on behalf of the cared for.

WHEN ASKED ABOUT WHAT SUPPORT CARERS FELT WOULD BE HELPFUL - CARERS RESPONDED:

Carers top 5 responses were:

26%	*Access to someone who could help them*
23%	*Access to information*
19%	*Support from other carers and groups*
16%	*Access to short breaks and respite*
16%	*Access to carers discount schemes and offers*

OTHER RESPONSES INCLUDED:

34% felt access to funding to support them as a carer would help

33% felt support to help them navigate the complexities of the health and social care system was needed

31% felt support with finance issues, benefits and employment would help them

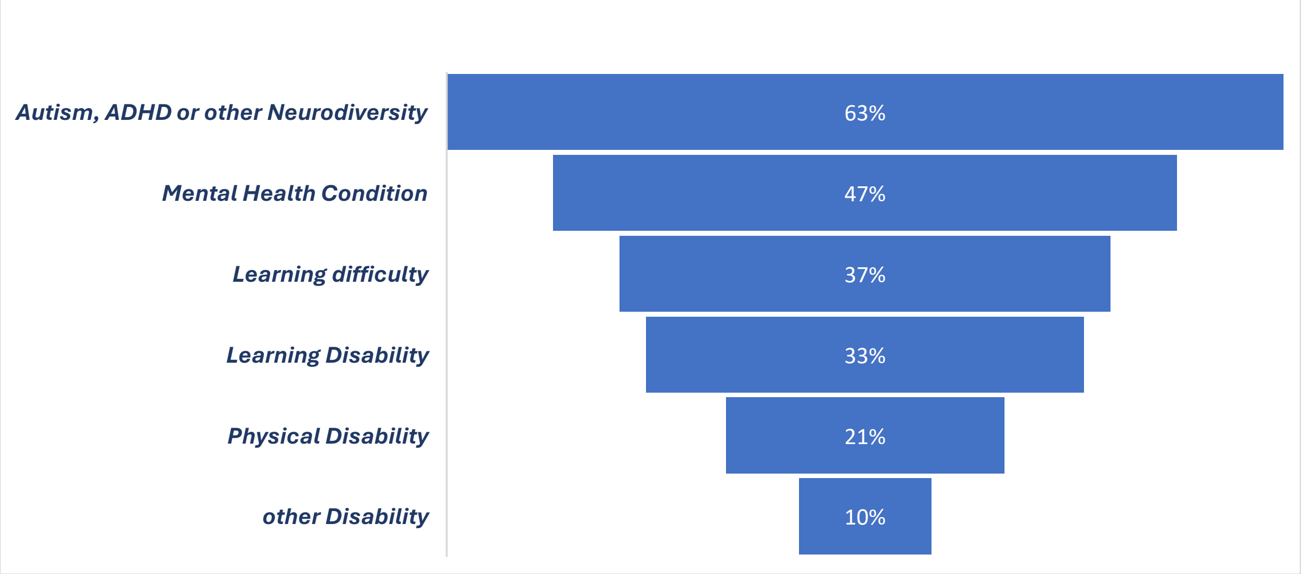
25% felt relevant training was needed

23% felt that help for the cared for person when they needed to attend an appointment would help

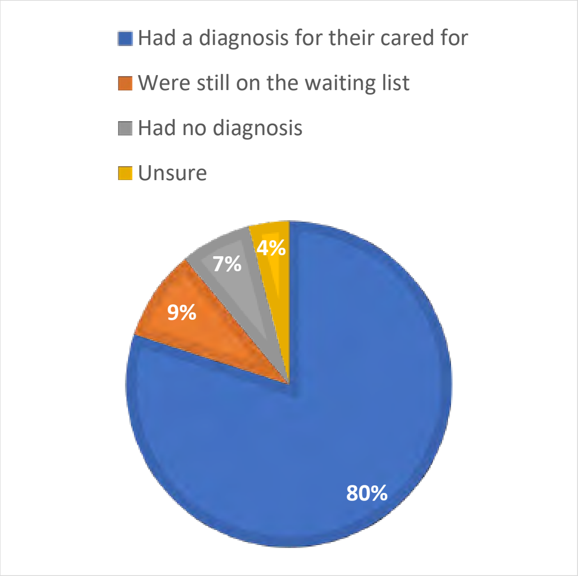
19% felt dedicated carer activities would be useful

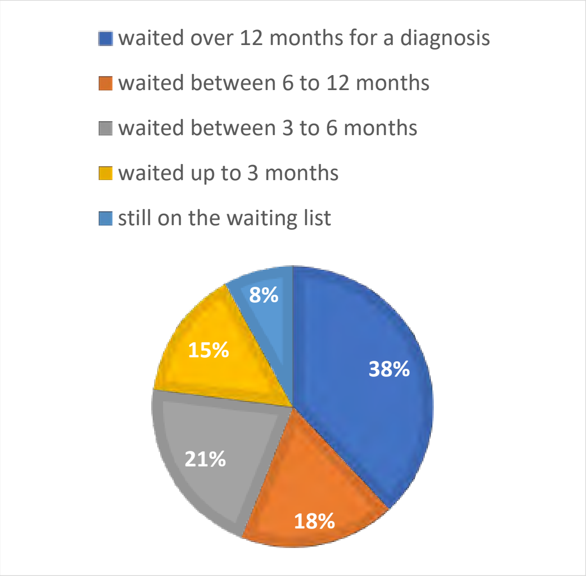
SECTION 4 – SPECIFICALLY FOR PARENT CARERS

DISABILITY OF THE CHILD OR YOUNG PERSON. (150 RESPONSES)

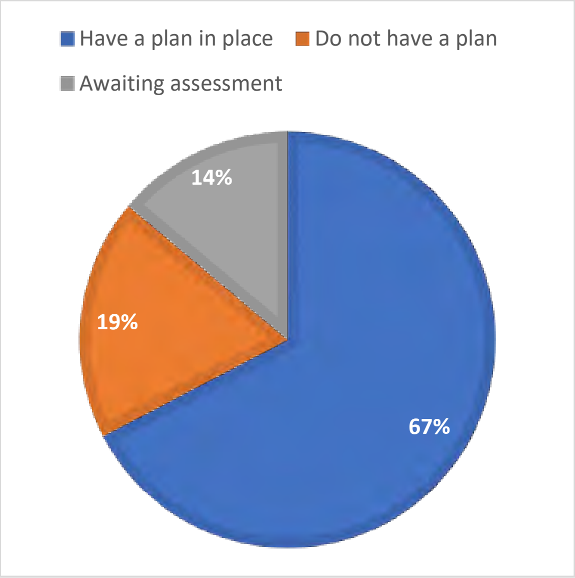


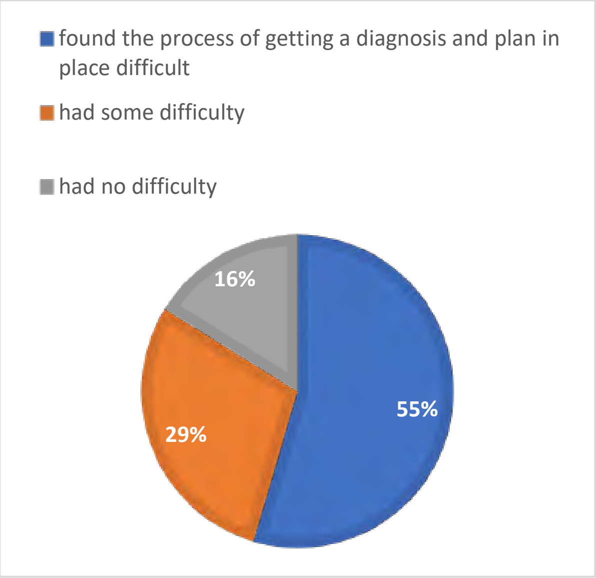
DIAGNOSIS – TIME TAKEN FOR DIAGNOSIS (144 RESPONSES)



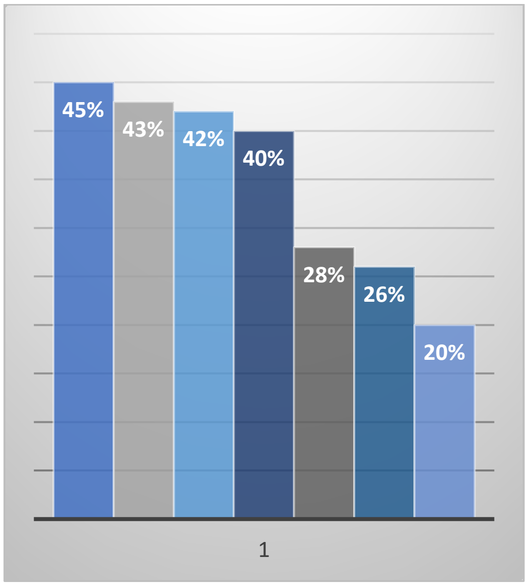


EHCP OR SEN PLAN – THESE QUESTIONS ASKED ABOUT IF A PLAN WAS IN PLACE AND HOW DIFFICULT THE PROCESS WAS.(140 RESPONSES)



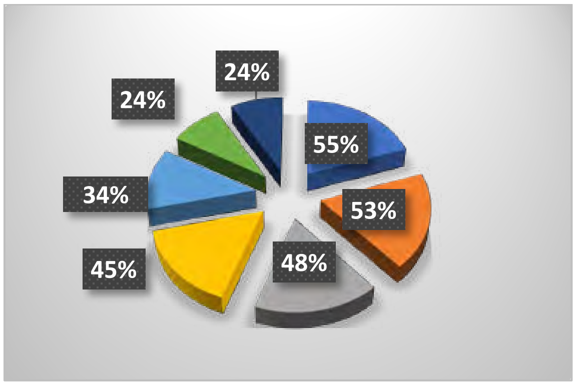


WHAT CARERS FELT HAD HELPED THEM AT THE BEGINNING OF THEIR JOURNEY. (138 RESPONSES)



- *45% -Having a good professional involved.*
- *43% -Having a good source of accessible information.*
- *41% -Having links with other parents who had the same or similar experience.*
- *40% -Having a knowledgeable person or team who was accessible.*
- *28% -Consistency of the professionals involved.*
- *26% -Face to face meetings- as part of friend's groups.*
- *20% -Having timely and accurate information about the disability.*

BARRIERS EXPERIENCED –(137 RESPONSES) THIS QUESTION FOCUSED ON WHAT CARERS FELT WHERE THE KEY BARRIERS IN THEIR JOURNEY OF ASSESSMENT AND SUPPORT FOR THEIR CHILD OR YOUNG PERSON.

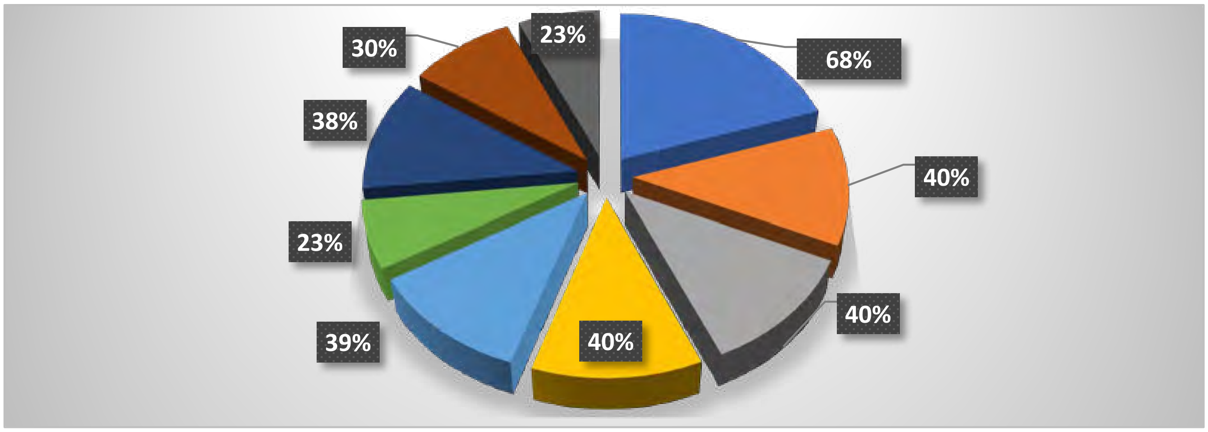


- *55% Poor Communication*
- *53% Lack of Consistent Support*
- *48% Lack of Information*
- *45% Delays in process*
- *34% Differing opinion of professional*
- *24% Social Work staff shortages*
- *24% School not engaging*

Having the school on side in supporting the diagnosis (141 responses) although not the highest response to this question, did produce a high response when parents were asked specifically about school interventions and support where perhaps a diagnosis or EHCP was still being considered. Many schools have programmes in place to support pupils with a disability and will proactively support parents and children. In the survey:

- *65% of parents expressed that having the school supporting them was helpful*
- *21% felt having the school supporting them had not been helpful*
- *15% were unsure*

CARERS IMPACTS –(145 RESPONSES) this question links to the one above but reflects the barriers that have a direct impact on the carer and their own health & Wellbeing.



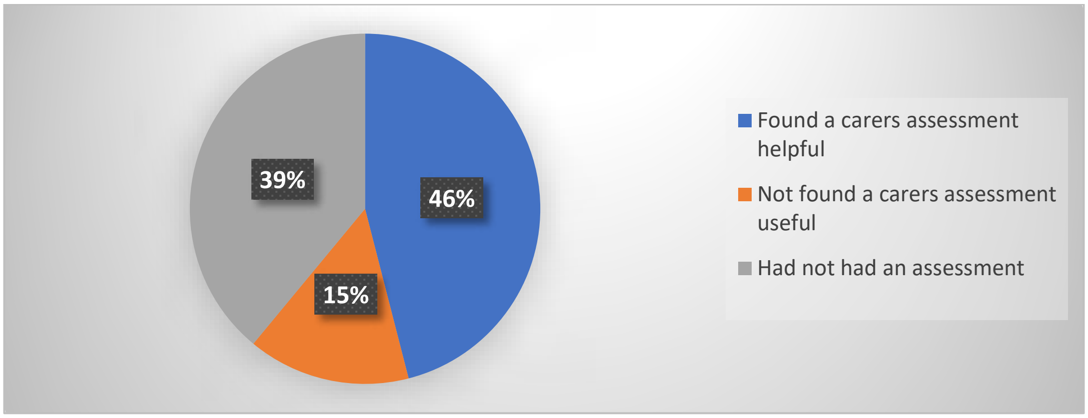
68% - Delay and support in securing a care agency	***40% - lack of a coordinated pathway between health & social care***
40% - Getting a support plan agreed which accurately describes the needs of the child or young person	***40% - Availability and information about respite and short breaks***
39% - Lack of information about a Direct Payment	***23% - Even where a DP is provided, no access to PA's***
38% - Lack of support for the parents' health & wellbeing	***30% - Lack of support for other children***
23% - Lack of consistent support or listening ear	

BREAKS FROM CARING – (154 RESPONSES)

The survey asked if carers had managed to have a break in the last 12 months: Carer Breaks are a consistent request by carers to support them with their caring role.

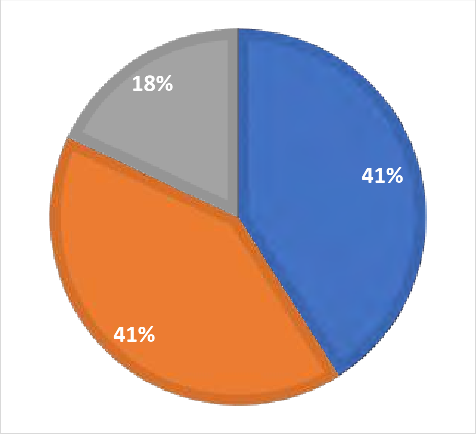
- 45% of carers have been able to access a break within the last 12 months
- 48% of carers have not
- 8% were unsure

CARERS ASSESSMENT ACCESSED –(153 RESPONSES)



Given that 46% of carers who had accessed an assessment had found it useful a focus going forward would be to consider the 39% who have not accessed an assessment to do so.

BEING RECOGNISED AS A CARER BY PROFESSIONALS. (158 RESPONSES)



41% of carers felt recognised

41% of carers felt not recognised

18% were unsure

Some parents expressed in the comments that they felt professionals

WHEN ASKED ABOUT OBTAINING THE RIGHT SUPPORT FROM PROFESSIONALS. (154 RESPONSES)

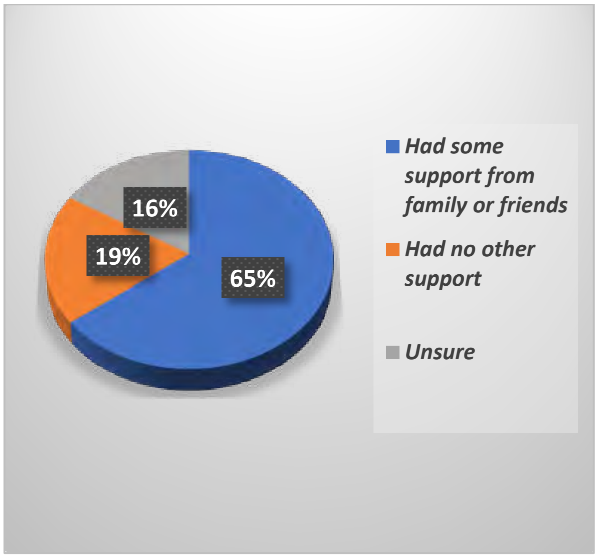
- 48% of carers expressed difficulty in getting support from social care when they needed it
- 29% of carers expressed that they struggled on occasion to get the support they needed

PERSONAL CONCERNS AND ISSUES AFFECTING THE CARING ROLE- (154 RESPONSES)

65%	*Lack of energy and difficulty sleeping or ability to rest*	
63%	*Trying to manage multiple commitments as well as caring*	
61%	*Caring for other children and family*	
58%	*Managing their own feelings and guilt when trying to manage competing demands*	
54%	*Feeling overwhelmed*	
53%	*Not having a break from caring*	
51%	*Creating their own barriers and feelings that they should be able to cope*	*Carers have described their inner dialogue – when you tell yourself you should be able to cope and not wanting to look like you cannot manage for fear*

		of criticism or decisions being taken away from you
47%	*Struggling with financial issues*	
37%	*Trying to manage conflicts with the school*	
21%	*Dealing with relationship issues*	
20%	*Experiencing conflicts with their partner - relationship issues*	
16%	*Housing issues*	

SUPPORT FROM OTHERS -FAMILY -FRIENDS. (154 RESPONSES)



My family are limited in what they can offer

My own parents try to help where they can, but they are elderly themselves so unable to really support me

Sometimes but I don't like asking

Very rarely one of my family members will have him for a few hours

DID CARERS STRUGGLE TO GET SUPPORT FROM STATUTORY AGENCIES. (151 RESPONSES)

Yes		48%
No		7%
On occasion		29%
No Services in place or accessed		19%

WHICH OTHER SERVICES DID CARERS APPROACH GO FOR SUPPORT. (153 RESPONSES)

GP -Consultant, Hospital doctor		50%
Health Visitor, Community Nurses		42%
Other health professional		39%
Social Services and/or Education		46%
School or college		34%
A Carers Service i.e. Carers Centre		46%
Family or Friends		36%
Other please describe in the comments box		7%
No services in place		9%

“Charities - basically went to anyone and everyone in complete desperation”

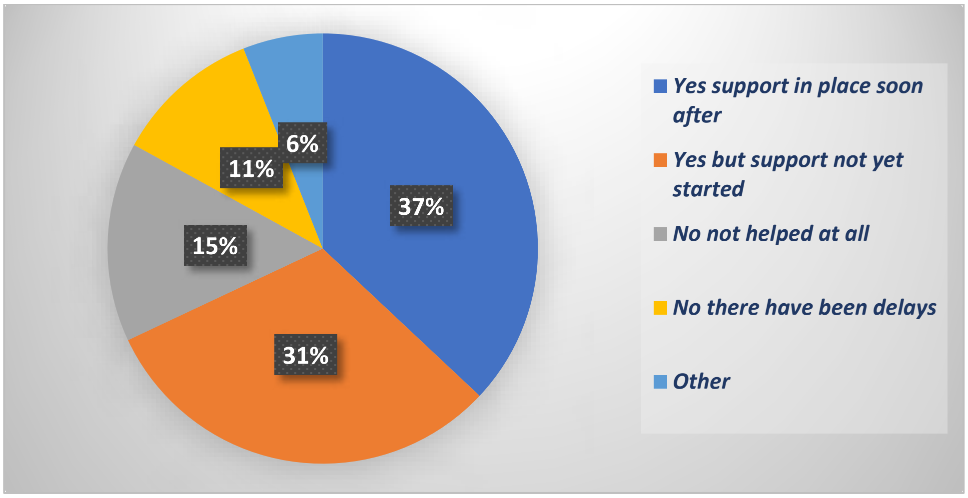
“Any help or service I found I try to take advantage of as I find everyone has something to offer in the way of information and insight”.

“I feel like I can ask the Carers Centre and ACES for help and support”

“Respite provision is very inflexible you have to book well in advance I.E. up to 6 months ahead, with no chance of changing the date at a later time”

“It was absolutely horrendous trying to get social care to do an assessment of need for our son. It took over 5 years”

HAVE YOU AN EHCP IN PLACE AND IF THIS ASSISTED IN GETTING THE RIGHT SUPPORT. (136 RESPONSES)



- *"When my 13-year-old was diagnosed there was no support in place. Our 2-year-old we have just been told to access a sensory workshop and there is no further support given whilst we are expected to be on a wait list of 84 weeks"*

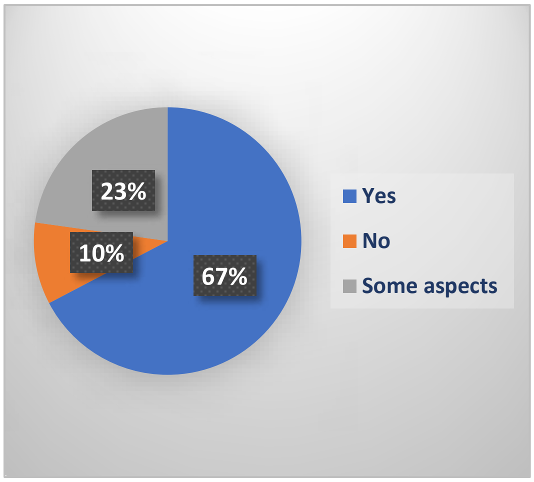
- *"The college are not flexible in the way they provide support"*

- *"The EHCP is entirely pointless. Nobody follows it and it is a complete battle to try and get it written (poorly) in the first place".*

- *"Even with Diagnosis of ADHD, ASC, Moderate Learning Disabilities, Sensory Difficulties, Dyslexia & Irlens Syndrome my son still didn't receive the correct support, not until he had a EHCP in place"*

- *"Once EHCP received I was able to get my daughter in the right school setting, which has helped 100%"*

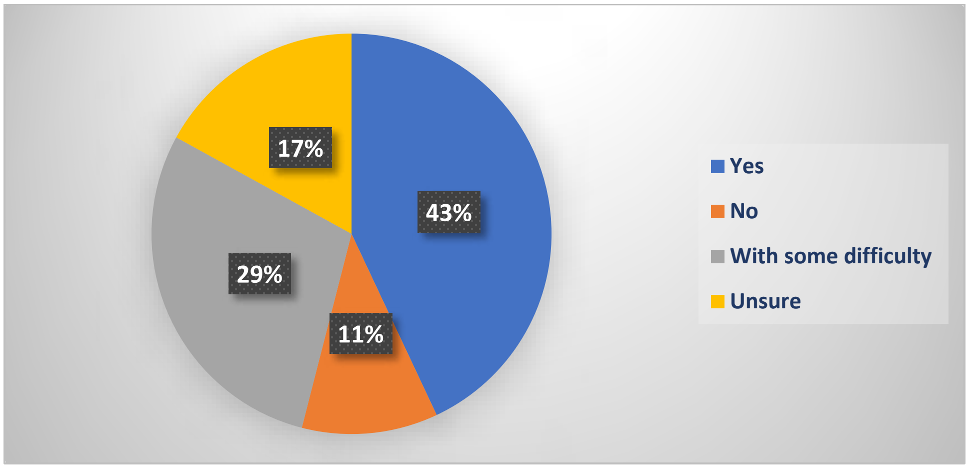
WAS THE PROCESS TO OBTAIN SUPPORT DIFFICULT TO NAVIGATE. (142 RESPONSES)



"Being treated with suspicion all the time and with an attitude of why I am bothering them"

"I had to train and educate myself on FASD and the EHCP procedure. Then I had to educate the professionals who were reluctant but once exposed they co-operated. This is not my job. I am not paid, and they are. They know such little".

WHERE NO PLAN IS IN PLACE HAVE THE SCHOOL BEEN SUPPORTIVE. (118 RESPONSES)



WHAT SUPPORT HAS HELPED THE MOST AND YOU SEE AS ESSENTIAL. (143 RESPONSES)

Support from people around me -family, friends etc	*62%*
Peer support from people who have had similar experiences	*41%*
An accessible and knowledgeable professional you can contact when needed	*54%*
Good Social Care Provision, Aiming High, or other services	*45%*
Accessible day time support, when needed, including out of school times	*29%*
Short breaks	*20%*
Planned and emergency respite provision	*15%*
Accessible health provision when needed	*21%*
Access to services like CAMHS in a timely way when needed	*24%*
Good sufficient information	*24%*
Consistent and good communication with professionals	*32%*
Available support from school	*25%*
Space as a carer to take time out or to work through issues with a helpful person or service	*27%*
Other, please describe in the comments box	*3%*

"Actual holistic family support from a knowledgeable and committed person who viewed our family and our difficulties in totality and was able to advocate for us amidst the circle of 'not us the other service' buck passing and recognised the whole family as an interdependent system where problems in one area cause difficulties in another".

"CAMHS crisis line is good but CAMHS appointments take too long to come through"

"Support FROM Sefton parent carer forum"

"Sefton Carers Centre"

HAVE YOU ACCESSED DIRECT PAYMENTS TO HELP WITH SUPPORT – (143 RESPONSES)

"Navigating this is exhausting and social care make it extremely difficult in using them … in the best way that supports... Social Care make you feel like you are a fraud if you dare step out of their unlawful line. They do not follow the CSADPA 1970 and expect DPs to be used on only a Day Centre, DP worker. They refuse to pay for transport ……. to and from places of respite, day care and treat me like a criminal when I do, even though I pay a huge client contribution into the pot".

"We have a good support worker now but unsure about long-term prospects and it was a real struggle to find someone suitable given the low wages offered by DP scheme"

"Hard to find personal assistance"

SECTION 5.

FOR YOUNG CARERS BETWEEN 16 -25

IMPACTS ON COLLEGE OR UNIVERSITY. (91 RESPONSES)

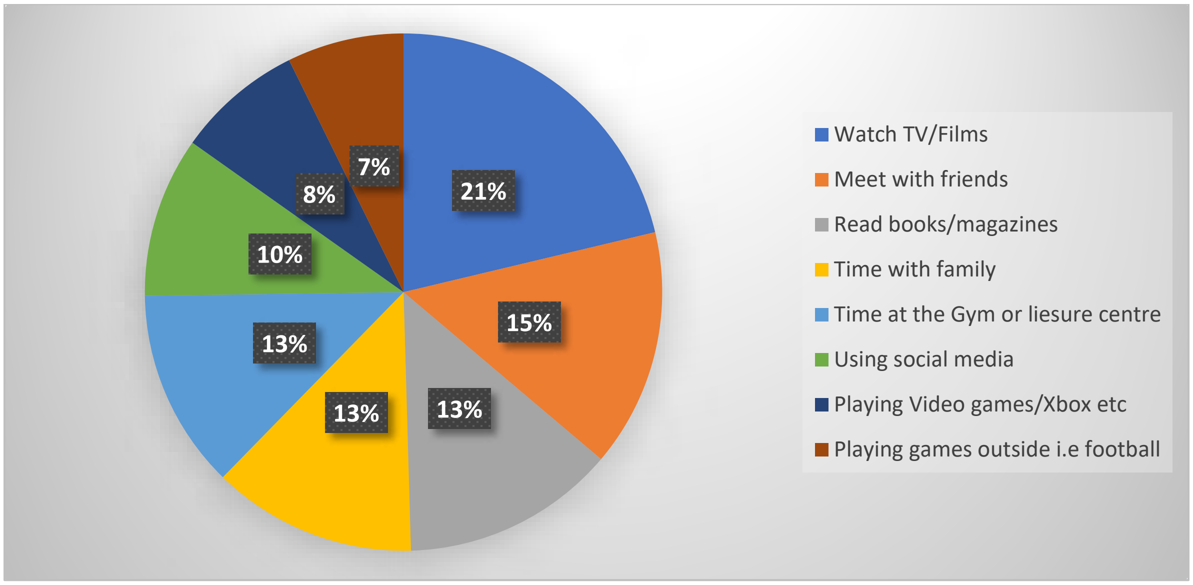
Yes -It affects my -- Attendance, Punctuality, Timekeeping/lateness		51%
I feel anxiety about being behind with studies or projects		44%
There is a lack of understanding by tutors or other staff		27%
I can have difficulty connecting with other students		19%
No Impact		20%
Other		7%

OTHER IMPACTS. (96 RESPONSES)

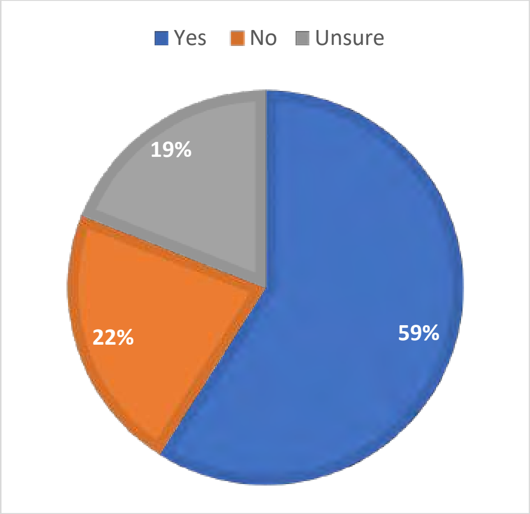
Having low confidence levels - low self esteem		40%
Finding it difficult being able to see your future or achieve your aspirations for the future		50%
Having worries over your future employability		46%
Having issues with lack of quality sleep - increased fatigue		54%
Having difficulty focusing when attending education due to		34%

worrying about your cared for when your not there.		
It restricts your ability to make friends or to see your friends		34%
It stops you doing things or going to places which may help your own well being ie the gym or social activities		43%
Having conflicting feelings or emotions for example feeling guilty when you might not want to care for your loved one		34%
Experiencing low or fluctuating moods		30%
Feeling anxious, stressed or depressed		42%
Feeling angry, upset or confused		23%
Feeling isolated and lonely		24%
Finding difficulty maintaining a personal relationships or thinking about moving out of the family home		24%
Ignoring your own needs, and not seeking help when you might need it, including health needs, or emotional/mental health needs		46%
No Impact		4%

ACTIVITIES, RELAXATION AND TIME FOR YOURSELF, WHAT DO YOU ENJOY. (96 RESPONSES)



DO YOU FEEL THERE ARE ENOUGH ACTIVITIES OR PLACES AVAILABLE TO TAKE TIME OUT OF YOUR CARING ROLE. (94 RESPONSES)



“Yes but I’m overwhelmed and always feel guilt”

“Everything is expensive”

WHAT ACTIVITIES WOULD YOU WISH TO SEE WHICH COULD HELP YOU MANAGE YOUR CARING ROLE. (94 RESPONSES)

Group meetings with people who understand		32%
One to one well-being support or therapy sessions, including support for your own physical and mental health		63%
Dedicated break times away from caring		38%
School based support e.g. homework and quiet lunch clubs		35%
Careers and employabilty advice and support		30%
Dedicated support in College or University to acknowledge and support carers		23%
Advocacy support - someone who can support you or speak on your behalf to lecturers about your situation and avoid penalties for things like lateness		34%
Short breaks and residential breaks with other young carers		27%
Activity days in the school holidays with other young carers		28%
WhatsApp or text messaging support		16%
Peer support groups		15%
Discount schemes for carers i.e. in some shops, holidays etc		38%
Discounts for cinema or leisure centres		28%

Relationship support and advice, for example personal relationships, relationships with your family etc		32%
Support with housing options, when considering moving out of home		23%
Support with other caring options, when and if you need it		16%
Other please add in the comments box		1%

WHAT TYPE OF SUPPORT DO YOU PROVIDE FOR YOUR FAMILY MEMBER – (98 RESPONSES) *carers could pick more than one option and so there will be some carers who will be doing multiple support roles.*

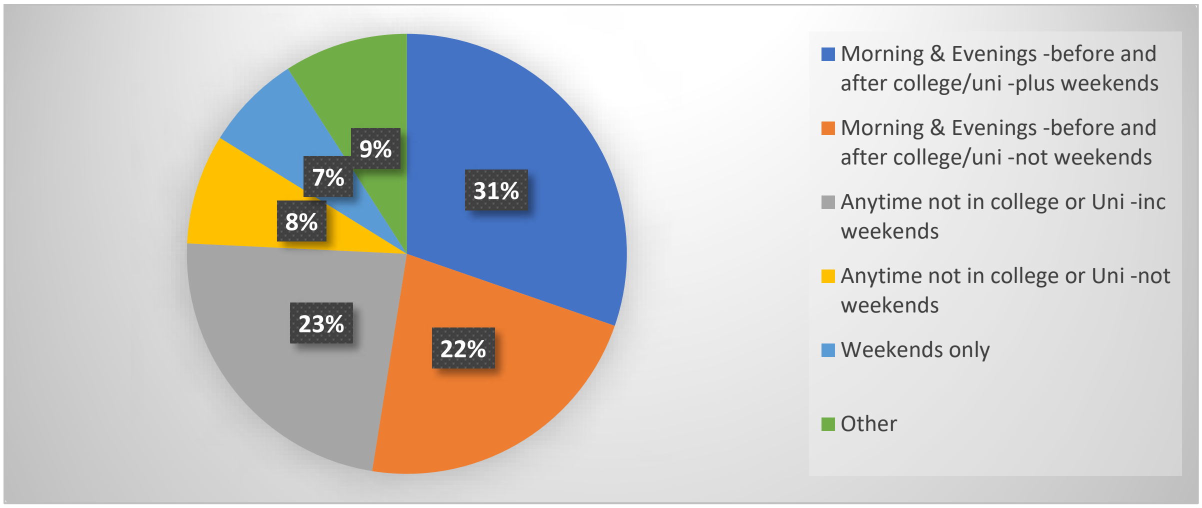
72%	Personal Care
69%	Practical Support
61%	Emotional Support
56%	Sibling Care
44%	Financial Support
42%	Support with treatments
39%	Support with mobility, moving and handling
3%	Other

“Providing care at crisis times when mental health deteriorates. Everything else has to pause for this”

Sibling support –

“I make sure I always have a range of activities crafts pre made up and a sensory play box ready so she is about to transition from one activity to the next we play games like I spy or looking for certain cars while or she will watch my phone why travelling. Getting home we ensure a craft activity is prepared for her so as she gets home sensory activity outside play on swing’s trampoline coupling board games”

WHEN DO YOU PROVIDE SUPPORT. (96 RESPONSES)



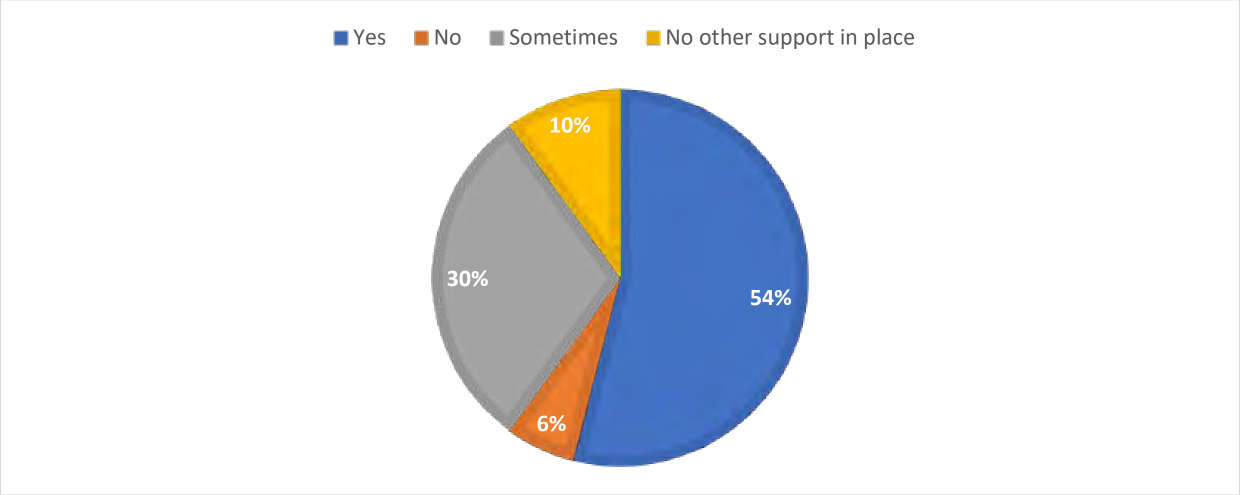
- *As and when needed throughout every day*
- *All the time I'm on standby*
- *I am s's only carer 24/7*
- *I support my mum with my brother and dad. I work part time and take my brother out I do gardening and shopping in between on days I don't work. I look after my brothers social needs*
- *I provide support throughout the day sometimes I can go 5 times a day depending on what is needed*
- *Because he is unpredictable and can become distressed and need support at any time*

WHAT OTHER SUPPORT IS IN PLACE. (96 RESPONSES.

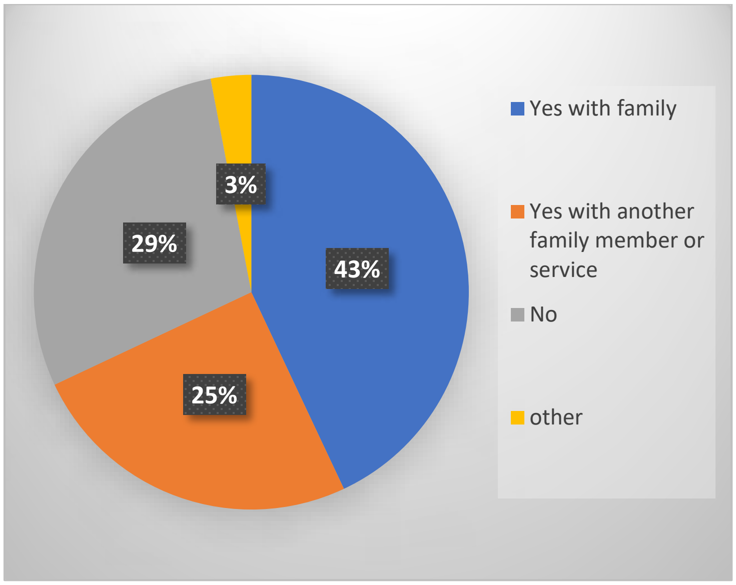
52%	An adult living in the same family
32%	A child living in the same family
33%	A relative/friend who does not live in the household
21%	Social Care support in the home during the day
18%	Social care support during the evening/nighttime
23%	Social care support outside the home during the day
23%	Healthcare support at home
14%	No services or other support in place
5%	Other

- *Safer family's*
  Sefton carers
  Early help
- *Day centre funded by direct payments*
- *My mum helps*
- *He gets pip which has helped some independence*

WHERE SUPPORT IS IN PLACE DOES THIS ENABLE YOU TO HAVE A BREAK FROM CARING. (98 RESPONSES)



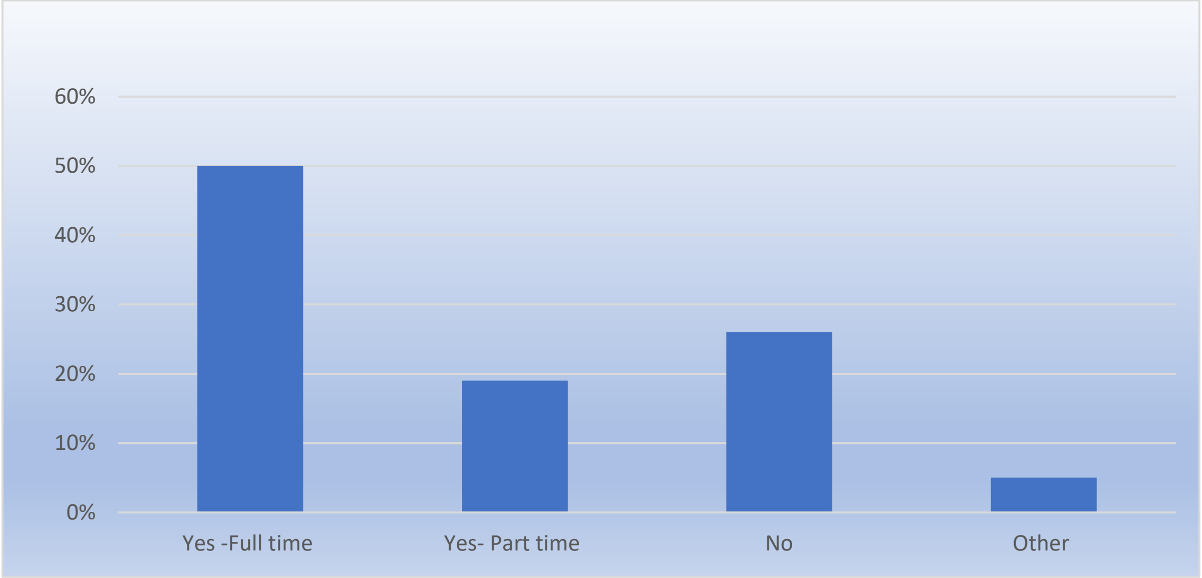
HAVE YOU OR YOUR FAMILY BEEN ABLE TO HAVE A BREAK OR HOLIDAY IN THE LAST 12 MONTHS. (97 RESPONSES)



Have a break, but every time we go away and come back the situation is worse, so don't like going away

First holiday in 5 years

DOES THE PERSON YOU CARE FOR WORK OR STUDY. (98 RESPONSES)

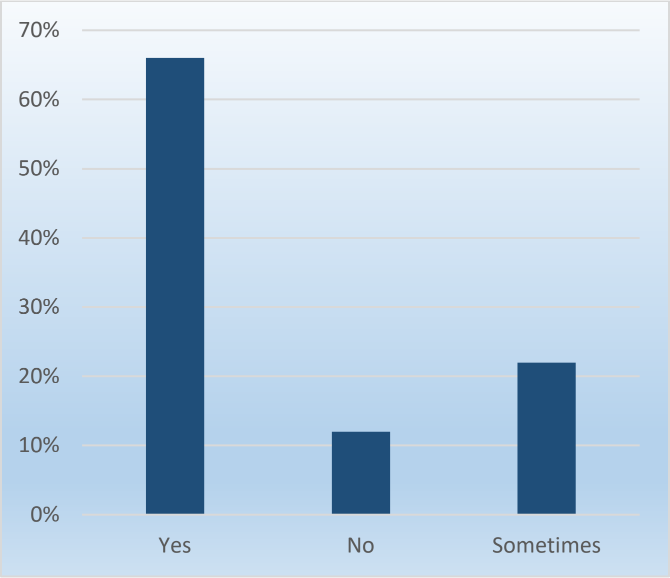


They study with my support

Cared for is still at school -sibling

DOES YOUR FAMILY STRUGGLE FINANCIALLY AND DOES THIS PUT PRESSURE ON YOU.

(96 RESPONSES)



66% Yes

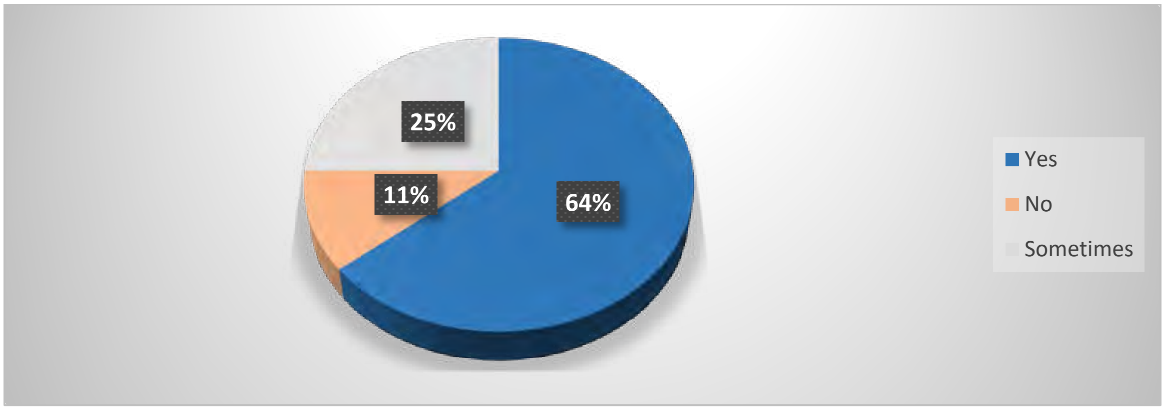
12% No

22% Sometimes

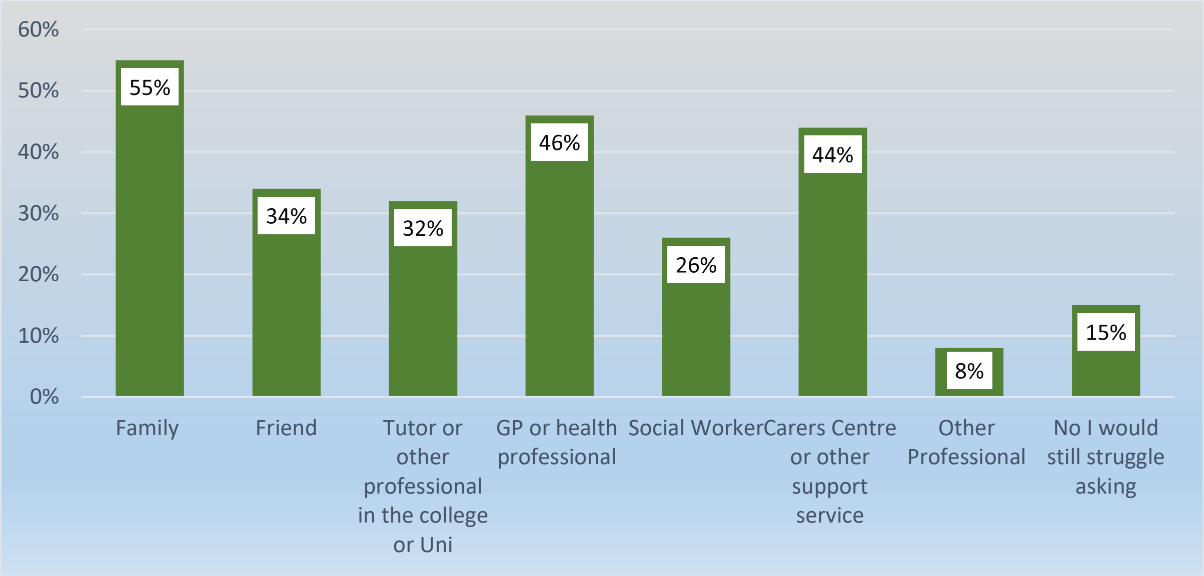
"She uses a lot of resources to keep her well entertained and calm and she flits from one activity to another so and can break things a lot as very clumsy"

"We have a tight budget"

DO YOU FIND IT HARD TO ASK FOR HELP SOMETIMES. (97 RESPONSES)



WOULD YOU STRUGGLE TO ASK FOR HELP NOW, AND IF DO WHO WOULD YOU FEEL COMFORTABLE APPROACHING. (98 RESPONSES)



- *We are a close family and try to work through as much as possible*
- *I've asked for help from lots of service, but they can't help because of our situation*

WHAT OTHER TYPES OF SUPPORT WOULD YOU LIKE TO SEE IF THESE WERE POSSIBLE. (99 RESPONSES)

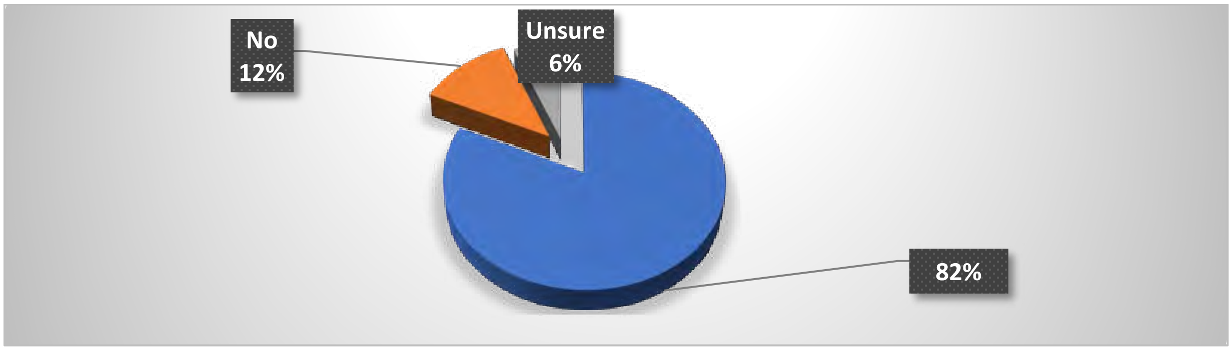
Good information and a knowledgeable professional who can support you when needed		58%
Access to planned breaks		44%

Access to a holiday		42%
Good support groups		35%
Discounts on membership to Gym or other leisure facilities		37%
Discounts on other things like cinema, or shops		34%
Access to good support for the cared for person		45%
Help with planning my future, including career choices and employment options		36%
Help with University application and housing options		20%
Access to therapy when needed for both physical and mental well-being		40%
Space to study		15%
Time for myself		34%
Meeting friends /Making Friends		30%
Relationship advice		7%
Advice on housing for when I might wish to leave home		9%
Information on support options for my cared for family member		17%
Other - please describe in the comments box		2%

SECTION 6.

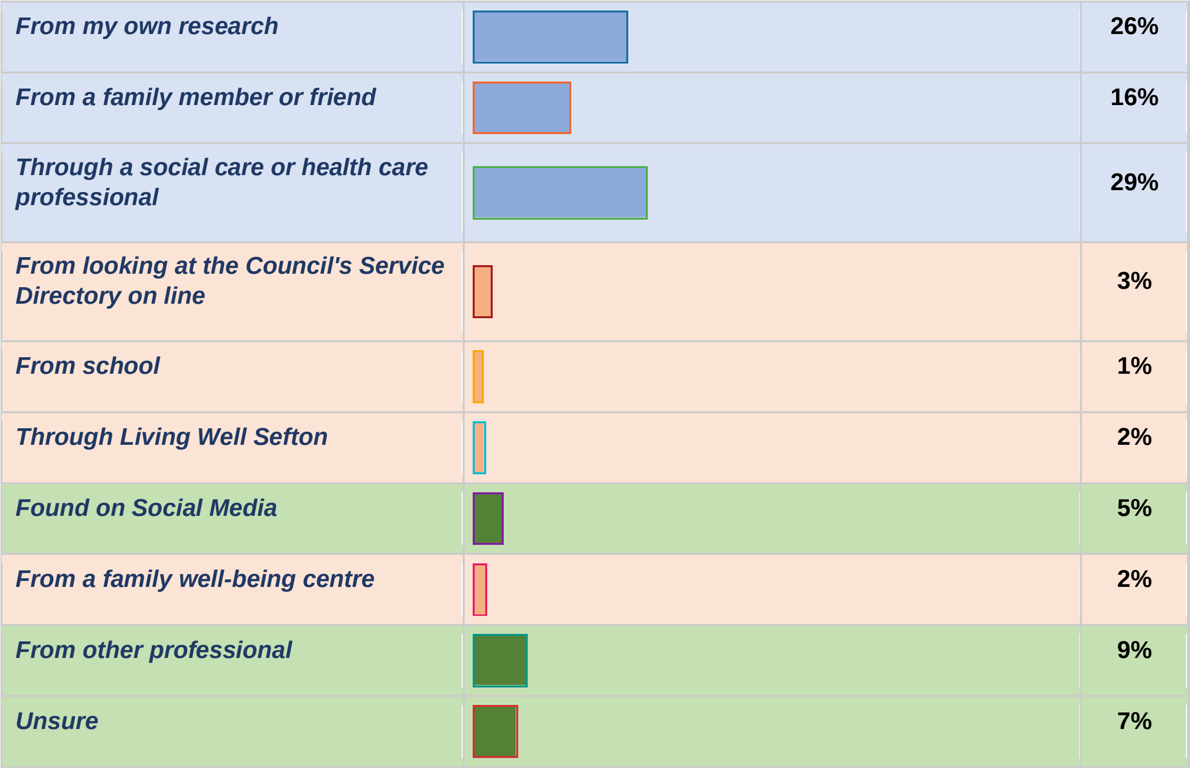
FOR ALL CARERS – REGARDING SERVICES PROVIDED DIRECTLY BY THE CARERS CENTRE

HAVE YOU ACCESSED INFORMATION OR SERVICES FROM SEFTON CARERS CENTRE, EITHER ONLINE OR THROUGH THE SEFTON SITES. (442 RESPONSES)



- *Still waiting for carers assessment to be completed.*
- *Initial help was very good with lots of booklets*
- *I had a lot of help - I still get phone calls every Tuesday*
- *They are very helpful and supportive*
- *Both online and in person they are fantastic I couldn’t praise them enough*
- *They are very helpful*
- *Very helpful friendly. Do their best*
- *The help they gave to fill in attendance loan etc application was invaluable.*
- *They have advised me where to access equipment to help with mobility.*
- *PIP application support was great*
- *They were very helpful with practical stuff*
- *I'm really assured they are there if needed. Thank you.*
- *Sefton Carers is an excellent source of information and support.*
- *I benefitted from support for a short break for a number of years and annual review. I also appreciated the Car*
- *Carers Centre in Waterloo, are so friendly and helpful.*
- *I have accessed the Life rooms in Southport through that found the coffee afternoon*
- *Don’t use internet for long periods as cant leave husband alone due to falls*
- *I do not have internet facilities*

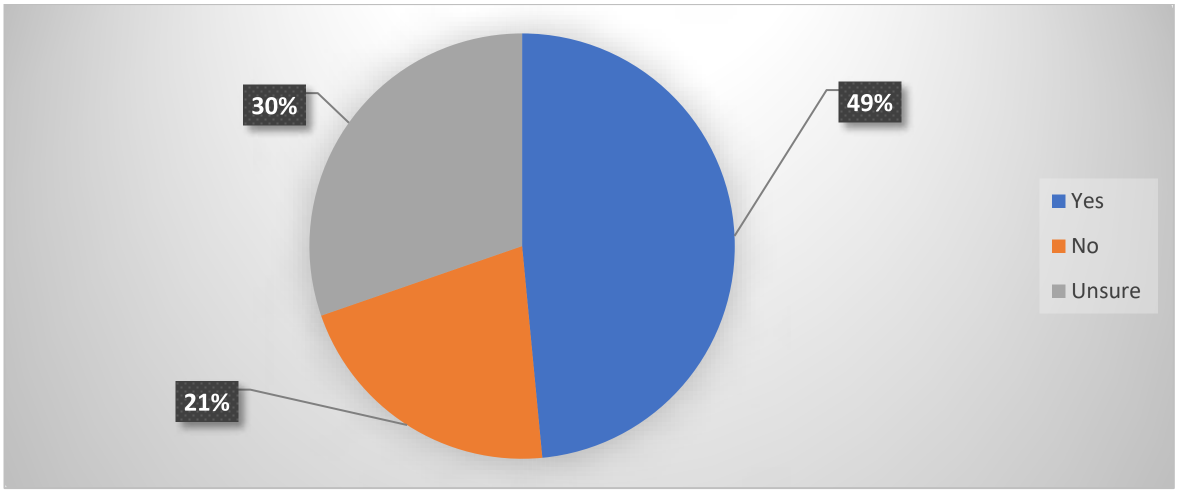
HOW DID YOU FIND OUT ABOUT THE CARERS CENTRE –(TOTAL RESPONSES 432)



From my own research	26%
From a family member or friend	16%
Through a social care or health care professional	29%
From looking at the Council's Service Directory on line	3%
From school	1%
Through Living Well Sefton	2%
Found on Social Media	5%
From a family well-being centre	2%
From other professional	9%
Unsure	7%

I was told about this from Early Help	*Sefton carers are in my local area.*
When I was made redundant the job centre told me	*A notice in my GP practice*
I've known about it for 20+ years	*Alzheimer society*
A friend who is a carer told me about it	*From the Voice of the Families group*
I assume that a social care or health care professional referred me.	*Woman from hospital*
From passing it on the bus going to and from Liverpool since it opened	*Met a lady in the pharmacy who insisted I contacted & registered*
Fire brigade	*Through an Occupational Therapist*
I am aware of Sefton Carers through working for Sefton CVS	*On discharge from hospital*
Through Sefton Carer staff visiting & talking to a M.N.D. Support group run by The Motor Neurone Disease Association for people living with the disease.	*From working in NHS*
From a local lawyer	*Through my Personal Health Budget support*
From works carer support group backed up with recent advert in Make the Most of Sefton magazine/newsletter	*As part of my PHB support*

DO YOU FEEL ENOUGH INFORMATION IS AVAILABLE ABOUT THE CENTRE AND SERVICES IT PROVIDES. (433 RESPONSES)



“The awareness & marketing of the carers centre should be better, whilst the centre itself is great not enough is known or promoted to the wider audience”.

“It's a great service but not well advertised”

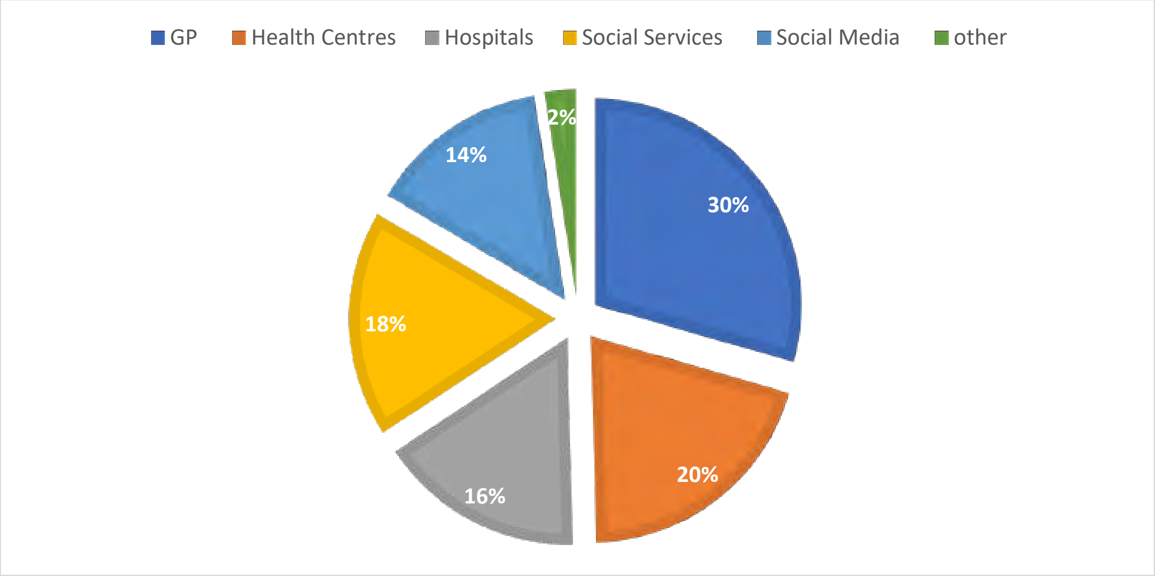
“No they are not easily found in my experience”

“It’s services need to be highlighted much more as they offer so much!”

“It needs more advertising Sefton carers centre is brilliant and help me a lot - without it I would be lost”

“I think sometimes services are available but navigating a caring role and accessing information on your own can be a struggle because you can be emotionally tired”

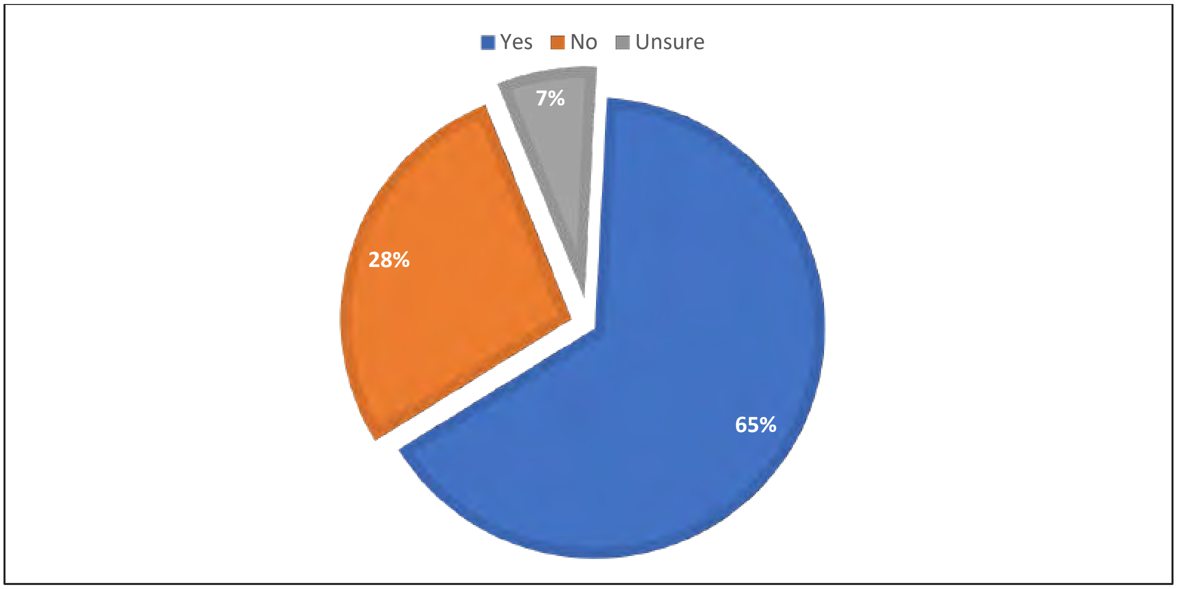
IF YOU STRUGGLED TO FIND OUT MORE ABOUT SEFTON CARERS CENTRE, CAN YOU SUGGEST WHERE YOU WOULD FEEL IT SHOULD BE MADE AVAILABLE. (385 RESPONSES)



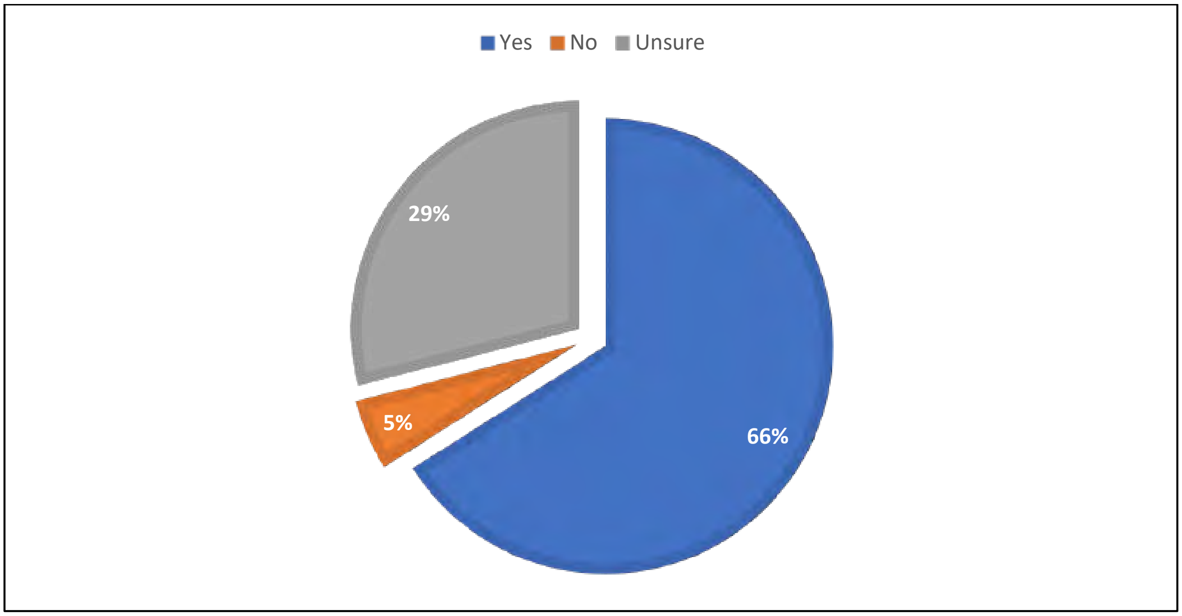
- *Any information boards e.g. supermarkets*
- *Text services*
- *Macmillan / support groups / Health and Wellbeing events*
- *They are so valuable; everyone should know about them.*
- *I rarely visit centres so social media would be useful*
- *Absolutely everywhere there just isn't much help out there and I know how busy they are, but more people should know about them*
- *As many places as possible*
- *Schools to reach young carers*
  Local colleges universities to reach the home students looking after a parent
  Church and other religious organizations notices and newsletters to reach older carers who take their cared for person to religious devices
  Pharmacy notice boards
  Social places like the Marine Football club Crosby, where all sorts of people gather at their social facilities and events
- *When your child gets diagnosis letter*
- *I have requested advice from Social Services and am awaiting an appointment from them. They told me that they do not normally have contact with carers until the matter becomes urgent.*

- ***Link from Council Website or more awareness. Also been challenging to contact the carers centre to update personal information.***
- ***Community Hubs: Libraries, Social & Leisure Centres, shopping areas, Transport hubs***

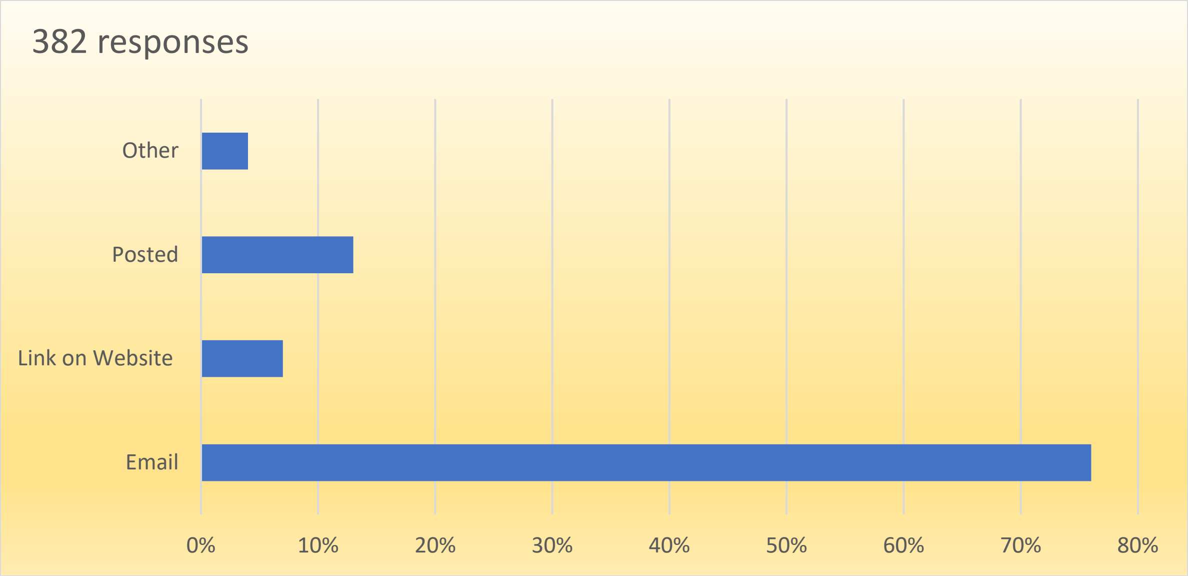
ARE YOU AWARE THAT SEFTON CARERS CENTRE PRODUCES A NEWSLETTER. (442 RESPONSES)



IF YOU ARE AWARE, HAVE YOU FOUND IT USEFUL? (362 RESPONSES)



WHAT FORMAT WOULD CONSIDER THE BEST WAY TO RECEIVE THE NEWSLETTER



- **An email to remind people the latest one has been published**
- **Sorry about the cost. But as an oldie I am not good with technology**
- **I don’t feel it is useful regardless of the format. Things advertised in it have either passed or are at unsuitable times.**
- **I've found it difficult to read on my phone**
- **On the website as well**
- **Or left on the front desk in carers centre**

WHAT SERVICES HAVE YOU ACCESSED THROUGH THE SEFTON CARERS CENTRE. (409 RESPONSES)

(Results will be affected by the overall numbers of carers in some areas i.e. young carers where the population is lower than older people registered. Withstanding this the three main areas that prompted significant response are the top three. Some carers will also have accessed multiple services).

Information only		34.96%
Information and Advice		57.95%
Welfare Benefits support		37.90%
Access to activities and training for carers		16.87%
Access to Carer Groups and coffee mornings		16.63%
Access to the Carers Support Team - Adults		12.22%
Access to Living Well Sefton		9.05%
Access to Carers Support Training -Adults		7.33%
Access to the Parent Carer team		11.49%
Access to the Parent Carer support groups		7.58%
Access to the Young Carers Team		8.31%
Access to the Young Carers Groups		6.11%

Access to Young Carers Activities	🟨	4.40%
Access to a Carers Assessment - Adults	🟧	11.74%
Access to a Carers Assessment - Parent Carers	🟩	6.60%
Access to a Young Carers Assessment	🟨	4.40%
Access to the Carers Voice Group	🟨	3.67%
Counselling Support	🟧	10.76%
Access to Listening Ear Service	🟩	5.62%
Access to the Energy Advice Service	🟩	7.58%
Access to Direct Payment Support and Advice	🟩	9.05%
Access to the Direct Payment Payroll service	🟩	5.38%
Access to Personal Health Budgets	🟩	6.85%
Access to Personal Health Budgets Payroll service	🟨	4.89%
Access to the Carers in Employment service	🟨	4.40%
Obtaining a Carers Emergency Card	🟧	15.40%
Accessing a Carers Emergency Plan	🟩	8.07%
Support for Hospital Discharge service	🟨	1.96%
Using the Positive Paint Service	🟨	1.96%

WOULD YOU RECOMMEND THE SERVICES TO OTHER CARERS. (417 RESPONSES)

76% of respondents said they would recommend the services to other carers

Only 1% of respondents said they would not recommend the services to other carers

7% of respondents said they would recommend some services but not others

15% of respondents were unsure

“I do recommend it to other struggling parents”

“I found the service and staff extremely helpful as a time of need and supported me through issues”

“The service provides many things that others do not and make you feel supported more than most”.

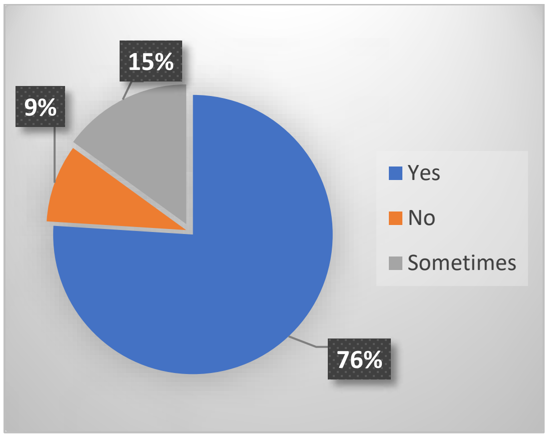
“The Alzheimer’s Society is more support”

“Very new to your service but certainly impressed so far”

“I received the Winter Warmer bundle - it was great and very, very useful”

“Support during Covid/advice”

WERE THE SERVICES PROVIDED IN A TIMELY MANNER. (395 RESPONSES)

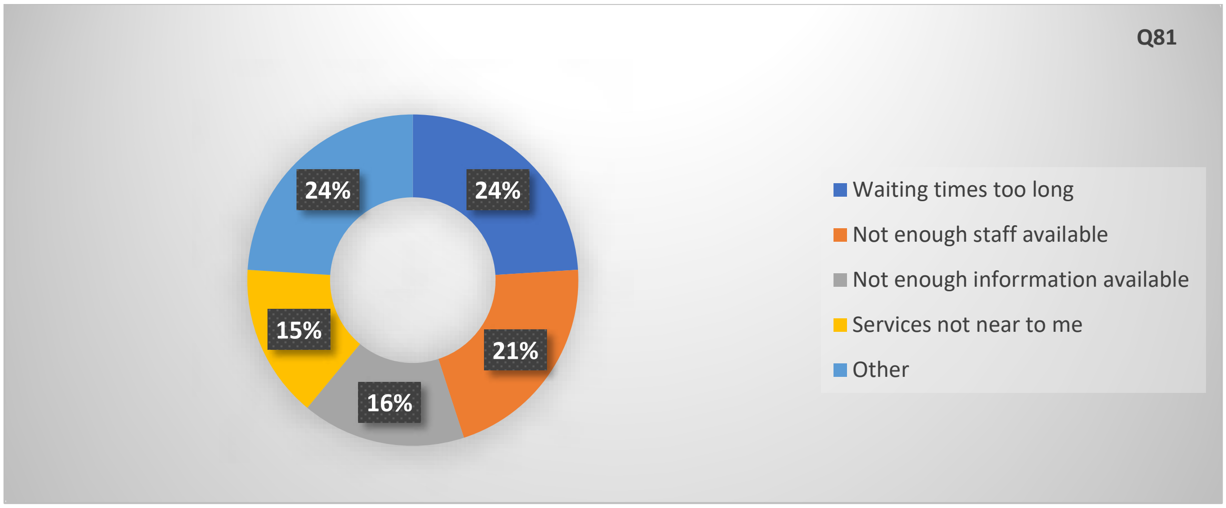


Sometimes appointments have to be rearranged due to sickness etc, with no one else available

My enquiry was dealt with very quickly. Thank you

Always on time

WHERE SERVICES HAVE NOT BEEN TIMELY CAN YOU IDENTIFY THE ISSUES – (274 RESPONSES)



- The times I gained information I needed staff were very helpful and knowledgeable. I got the information I needed at the time I asked
- I have always found the response from the staff to have always been excellent
- Cannot find any faults with the service provided by my local care centre
- some services are hard for us to access- I don't drive - my husband is not mobile - I have social anxiety

IN WHAT WAYS WOULD YOU SAY THE SERVICES WERE VALUABLE TO YOU AS A CARER.

(387 responses) carers could select multiple responses

They are a lifeline	27%
They are there when I'm stuck or struggling in my caring role	34%
They help me to navigate the complexity of becoming a carer	25%
They help me to better understand and navigate the health & social care systems and services	26%
They help to direct me to the right place or team when I am struggling	26%
The staff are helpful and always positive	48%
The staff really care and often go above and beyond to help	31%
The staff are approachable and friendly	48%
The staff are accessible when I need advice or support	30%
The staff make me feel like a valuable person	24%
The staff are all professional, informative and knowledgeable	33%
They help me to get more support or help	25%
They help me to care with the right training	7%
They have connected me with others and I have found good friends and peer support	9%
Training has helped to care for my cared for	7%
Activities are always well planned and give me a break from my caring role	6%
I have accessed support with benefits to help me manage my finances	11%
Gaining help with energy costs and advice has kept me warm through the winter	9%
Help with Direct Payments and Personal Health Budgets and Payroll has helped to keep services working	10%
Having a Carers assessment has really helped me to value my role and where possible access more support	15%
Other - please outline in the comments box	7%

HAVE THERE BEEN ANY UNHELPFUL ASPECTS OF THE SERVICES. (284 RESPONSES)

The services not near to me and are too far away		*32%*
The services are not sufficient		*13%*
Staff are not always helpful		*8%*
I have found it difficult to contact the centre		*14%*
I struggle to navigate the website		*13%*
I need more support than is available from the centre		*22%*
I have found communication is poor		*8%*
There are not enough staff		*18%*
Other - please describe in the comment box		*26%*

“Carers don’t ask for help until they NEED it and then you have to wait ages”

“As ever, there appears to be insufficient funding to provide the level of service that is probably needed”

“Website needs to be more concise and updating. Too generalised”

“Sometimes I have felt that communication is poor and takes too long to get a response”

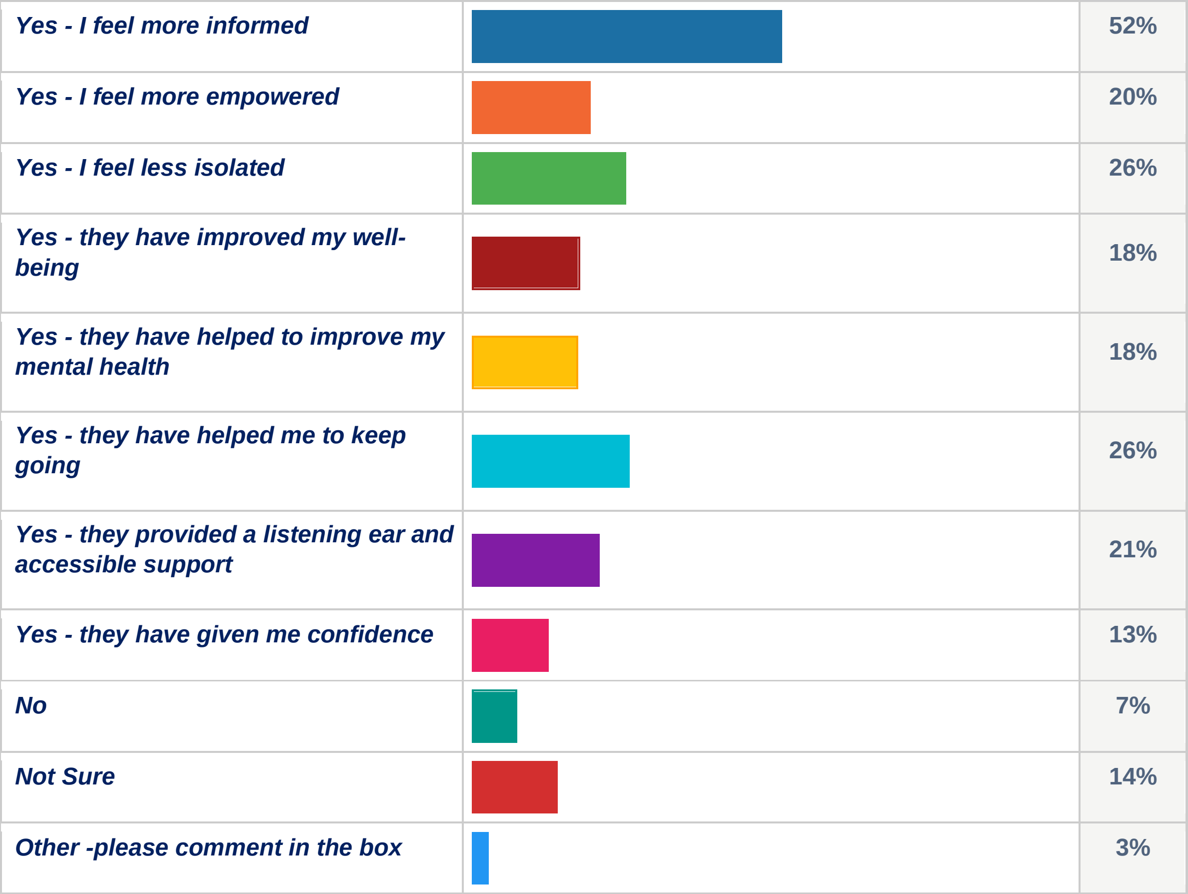
“The staff are excellent, but the scheme is clearly underfunded”.

“I find it difficult to access the courses offered, more online options would be helpful, particularly if there was an option for them to be recorded and watched online”.

“The service does not have the finances available to pay for respite breaks - not the fault of the carers service”

DO YOU FEEL ACCESSING THE SERVICES HAS HAD A POSITIVE IMPACT ON YOU

(399 responses) – carers could select multiple responses



Yes - I feel more informed	52%
Yes - I feel more empowered	20%
Yes - I feel less isolated	26%
Yes - they have improved my well-being	18%
Yes - they have helped to improve my mental health	18%
Yes - they have helped me to keep going	26%
Yes - they provided a listening ear and accessible support	21%
Yes - they have given me confidence	13%
No	7%
Not Sure	14%
Other -please comment in the box	3%

- **Coffee mornings and help knowing I can ask a question is helpful. They have given young carer son support with equipment for work etc. princes trust**
- **Really don't know how I'd manage with the complicated Benefits system on my own. Priceless support that really took the strain off me when life is such a struggle**
- **A very good service**
- **Knowing my youngest has activities that support her gives me relief**
- **Coffee mornings and help knowing I can ask a question is really helpful**

CAN YOU PROVIDE ANY SUGGESTIONS AS TO HOW WE CAN IMPROVE OUR SERVICES (104 RESPONSES)

- **Provide a sitting service again**
- **More staff to answer queries and return phone calls**
- **Help with trying to get carers discount or a blue light card which would help carers**
- **Carers ID card. I use my work ID card to 'prove' I am a carer**
- **More local services and more varied activities needed. Would be helpful if they reached out to check your coping and if any help is needed. It's not always easy to ask for help**
- **Keep in contact not just send out a newsletter.**
- **Getting in touch more with dual carers and letting them know if there is anything they may be able to access and what may be available in the form of grants etc. we don't always know what's available and could miss vital support that could make a huge difference. Website update.**
- **More staff to answer queries and return phone calls**
- **More support initially on accessing financial support**
- **Please get the newsletter out via email 'on time'!! with an up-to-date list of activities**
- **Better promotion of the Carers Centre, the support available and Social Hub**
- **A board showing all staff at the carers, with photos and roles would be helpful**
- **Reduce waiting times for carer assessments - a triage system would be useful.**
- **Having dedicated advisors for specific needs ie dementia**
- **Communication**
- **Strengthen professional training for employees to improve their communication skills and emotional support capabilities.**
- **establish systematic feedback channels, regularly collect the opinions of caregivers and caregivers, and improve services in a timely manner.**
- **Digital tools: introduce advanced management systems to improve work efficiency, such as nursing record system, appointment management software,**
- **Explore the possibility of providing remote counselling and support services to assist populations that cannot be physically present.**

- **Improve the infrastructure of the centre to ensure a comfortable and safe environment.**
- **provide more comfortable rest and communication space for caregivers and caregivers.**
- **Hold more community events to promote communication and support among caregivers.**
- **Open information: provide the public with detailed information on service contents, charging standards and activity arrangements to improve transparency.**